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ABSTRACT

This document is a resource guide to disabilities studies, an approach to disability which seeks to examine the social, economic, and political forces that for years have served to marginalize and oppress people with disabilities. Following an introduction that explains the field of disability studies, Section 1 is an annotated bibliography of 13 disability studies texts and a list of 14 additional recent publications. Section 2 is an annotated bibliography of 12 feminist disability studies and Section 3 describes 11 autobiographies and personal narratives. The following section describes eight movies and documentaries related to disability studies. A list of 24 more mainstream films is also included in this section. Section 5 offers fairly detailed descriptions of classes, programs, or concentrations in disabilities studies held at eight institutions. Data include contact information, program emphasis, and program requirements. The next three sections describe seven journals and magazines, nine organizations, and six Internet resources concerned with disability studies. Attached are the following article reprints: "Disability Studies and Mental Retardation" by Steve Taylor; "Disability Studies: Introduction" (Lennard J. Davis and Simi Linton); "Disability Studies: Expanding the Parameters of Diversity" (Simi Linton and others); "(Dis)Abling Images" (Terry Collins and others); "Integrating Disability Studies into the Existing Curriculum: The Example of 'Women and Literature' at Howard University" (Rosemarie Garland Thomson); "Silence Is Not without Voice: Including Deaf Culture within Multicultural Curricula" (H. Dirksen, L. Bauman and Jennifer Drake); "A Review of Deaf Studies Curricula" (H. Dirksen and L. Bauman); and "A Review of Harlan Lane's The Mask of Benevolence': Disabling the Deaf Community" (Lennard J. Davis). (Contains approximately 350 references.) (DB)

ED 422 708

INFORMATION PACKAGE ON DISABILITY STUDIES

PREPARED
BY
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AND
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August 1998

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INTRODUCTION

Over the past several decades, what we now refer to as "disability studies" has been a powerful influence on policy and practice in regards to people with disabilities. Disability studies has evolved as a means of addressing how people with disabilities have been treated historically and how they continue to be treated. Once seen through a medical model as people who are sick and in need of a cure, through a sociological model where people with disabilities are labelled and stigmatized by others, or through a psychological model where their experiences have been individualized and pathologized, people with disabilities are now being seen through different perspectives. Although medical and psychological models are still present, they are being resisted by a relatively new field called disability studies, its philosophy being that disability is a social construction. While disability studies does not deny that there are differences, either physical or mental, between people, they argue that "the nature and significance of these differences depend on how we view and interpret them" (Bogdan and Taylor, 1994). Therefore, rather than seeking to "fix" a person or to separate him or her from the rest of society, a disability studies perspective would seek to problemitize society rather than the individual. The solution therefore lies not in the person, but rather in breaking down the barriers that limit people with disabilities from full participation in their communities and in society in general.

Disability studies seek to examine the social, economic, and political forces that for years have served to marginalize and oppress people with disabilities. The field has emerged over the last several years, drawing on theories and perspectives from sociology, social science, women's studies, cultural studies, and education. It often focuses on the idea

that people with disabilities are a minority group who has been discriminated against. In this sense, the study of disability is similar to the study of race, class, and gender inequalities. In addition, disability studies provide the intellectual and methodological tools needed to create disability research and policy. The theories and philosophies of disability studies can then be applied to real issues in the law, in community inclusion, and in public policy.

The field of disability studies continues to grow and change. Recent additions to the field such as feminist disability studies and cultural studies have challenged "traditional" disability studies, and have forced the field to be more inclusive of different perspectives and positions in society. Moreover, disability studies most often focuses on issues around people with physical, rather than cognitive disabilities. One major challenge for the future of disability studies is the inclusion of the experiences of people with cognitive disabilities and how they shape this emerging field.

This package provides current information about the field of disability studies. In order to address this next challenge to disability studies, we have annotated very recent books (and just a few journal articles) about disability studies. They are divided into the following sections: disability studies texts, feminist disability studies, personal narratives/autobiographies, and movies and documentaries. Next, we have included a number of academic programs around the country which offer coursework and degrees in disability studies, as well as a list of journals and magazines and membership societies all pertaining to disability studies. Following this is a small section on Internet resources on disability studies. At the end, we have included an article by Steve Taylor from Disability Studies Quarterly regarding the construct of mental retardation and disability studies. Also

included in this reprint is a selected annotated bibliography that includes information on a number of books that address the same issue. The last section is a reprint of several articles from Radical Teacher, which recently devoted a large section of its publication to the field of disability studies.

Reference

Bogdan, R., & Taylor, S. J. (1994). The social meaning of mental retardation: Two life stories. New York: Teachers College Press.

Disability Studies Texts

The following section is comprised of books that could be used as "text books" for a disability studies course. Most of them are edited books that cover a variety of topics such as disability rights, identity politics, cultural studies and disability, social perspectives on disability, and perspectives of people with disabilities. Also included are a number of fictional pieces and poetry. It is worthy of note that the majority of this material is written from the perspective of or includes the perspective of only those with physical disabilities. Unfortunately, over the past several years, "texts" such as these which include developmental disability and disability studies have not been published. For a disability studies perspective (from less recent texts) which incorporates developmental disabilities, see the annotations by Steve Taylor and Perri Harris which are located at the end of this information packet.

TITLE: Nothing about us without us: Disability oppression and empowerment

AUTHOR: Charlton, J. I.

PUBLICATION INFORMATION: 1998

University of California Press
2120 Berkeley Way
Berkeley, CA 94720
FAX 510-643-7127
http://www-ucpress.berkeley.edu/

The author uses a disability rights standpoint to discuss the international oppression of people with disabilities. He provides a theoretical framework for understanding disability oppression not as something that has come from the attitudes of people without disabilities, but because of systems and structures of oppression from which these attitudes stem. He uses interviews with disability rights activists from around the world to back his argument.

TITLE: Speechless: Facilitating communication for people without voices

AUTHOR: Crossley, R.

PUBLICATION INFORMATION: 1997

Dutton
Penguin USA
375 Hudson Street
New York, NY 10014
http://www.penguin.com

Rosemary Crossley has been a pioneer of and outspoken advocate for facilitated communication since the 1970s. Her latest book, Speechless: Facilitating communication for people without voices, is an in-depth look at the experiences of 18 individuals who use facilitated communication. She describes the frustrations and complexities they face in their attempt to make themselves understood by others in their environment. She also explains the process of using facilitated communication, answering many of the questions raised about FC and demystifying many of the aspects of it that have troubled others.

TITLE: The disability studies reader

AUTHOR: Davis, L. J. (Ed.).

PUBLICATION INFORMATION: 1997

Routledge
29 West 35th Street
New York, NY 10001
212-216-7800
FAX 212-564-7854
http://www.thomson.com/routledge

This edited reader is a collection of classic and new essays, as well as fiction and poetry, in the field of disability studies. This perspective places disability in a political, social, and cultural context that theorizes the construction of disability in this society. The authors address such areas as feminist theories of disability, the construction of deafness, and disability as metaphor. The book is divided into seven sections, including historical perspectives, politics of disability, stigma and illness, gender and disability, disability and education, disability and culture, and fiction and poetry. This is progressive reading, but it should be of note that it is traditional in the sense that disability studies translates to "physical disability studies" and there is little mention of developmental disability.

TITLE: Staring back: The disability experience from the inside out

AUTHOR: Fries, K. (Ed.).

PUBLICATION INFORMATION: 1997

Plume
Penguin Putnam Inc.
375 Hudson Street
New York, NY 10014
http://www.penguin.com

This book, edited by Kenny Fries, explores the experience of disability through writings by contributors who have disabilities. The collection includes nonfiction, poetry, fiction, and drama by such authors as Nancy Mairs, John Hockenberry, Anne Finger, Adrienne Rich, Mark O'Brien, and Marilyn Hacker. Each chapter explores disability not as something that limits one's life, but as an experience all its own. Fries considers the theme of this edited book as one of human connection, "connection with the past, connection with one another, connection with our bodies, connection with ourselves."

TITLE: The disabled God: Toward a liberation theology of disability

AUTHOR: Eiesland, N.

PUBLICATION INFORMATION: 1997

Abingdon Press
201 Eighth Ave. South
P. O. Box 801
Nashville, TN 37202-0801
1-800-251-3320

Through this book, Eiesland, who became disabled as a child when she had polio, helps the reader to see how the "hidden history" of conventional bodies living ordinary lives with grace and dignity, disgust and illusion, can make for both a theological and pastoral contribution. Arguing for a liberation theology, she calls on us to move away from our defining of people with disabilities as people who need to adjust to a minority group that is subject to social stigmatization. While her examples tend to be based on the experiences of people with physical disabilities, what she has to say also is insightful for those working to include people with developmental disabilities in faith communities.

TITLE: Disability and culture

AUTHORS: Ingstad, B., & Whyte, S. R. (Eds.).

PUBLICATION INFORMATION: 1995

University of California Press
2120 Berkeley Way
Berkeley, CA 94720
FAX 510-643-7127
http://www-ucpress.berkeley.edu/

This edited book takes a global look at disability. Each chapter reflects understandings of disability from different cultures. Its anthropological focus examines the relationship between disability and culture, explaining disability in terms of social processes from a multicultural perspective. Contributing authors, who have done research in places such as Borneo, Kenya, Uganda, Nicaragua, as well as Europe and North America, explore the meanings of different types of disabilities to different cultures, and seek to understand the assumptions about humanity and personhood derived from their understandings of disability.

TITLE: Claiming disability: Knowledge and identity

AUTHOR: Linton, S.

PUBLICATION INFORMATION: 1998

New York University Press
70 Washington Square South
New York, NY 10012-1091
1-800-996-6987
FAX 212-995-3833
E-Mail: orders@nyupress.nyu.edu
http://www.nyupress.nyu.edu

In this new book, Simi Linton studies disability in relation to identity. She argues that disability studies must understand the meanings people make of variations in human behavior, appearance, and functioning, not simply acknowledge that these variations "exist." Linton explores the divisions society constructs between those labeled disabled and those who are not. She avoids a medicalized discussion of disability and promotes the notion that people with disabilities need to claim their identities as disabled and as contributing members to the understanding of disability as a socio-political experience.

TITLE: Disability studies/Not disability studies

AUTHOR: Linton, S.

PUBLICATION INFORMATION: 1998

Disability & Society, 13(4), 525-540.

In this article, Simi Linton seeks to define the boundaries between what should be considered disability studies and what should not. For reasons that she outlines, she proposes that curriculum and research that emphasize intervention should be viewed as separate from disabilities studies, which is a socio-political-cultural examination of disability. Linton advocates a liberal arts-based model similar to that which frames women's studies and African-American studies.

TITLE: End results and starting points: Expanding the field of disability studies

AUTHORS: Makas, E., & Schlesinger, L. (Eds).

PUBLICATION INFORMATION: 1996

Society for Disability Studies
c/o Robert Scotch
School of Social Science
University of Texas
Box 830688, Mail Station GR3.1
Richardson, TX 75083-0688
http://www.wipd.com/sds/

This edited book is comprised of chapters from extended abstracts of some of the presentations given at the Society for Disability Studies in Rockville Maryland in 1994. The authors discuss numerous topics relating to disability studies, although the focus is almost exclusively physical disabilities. The book is divided into sections, including: Disabling and Nondisabling Images of Disability, Family Reactions to Disability, Cultural Differences in Response to Disability, Acknowledging Challenges to Self Determination, A Progress Report on the ADA, Increasing Access to Services, Designing Relevant Research, Expanding Approaches to Disability, Contact and Communication as Vehicles for Change, Self Definition and Self Support, and The Power of Community as an Agent of Social Change.

TITLE: The body and physical difference: Discourses on disability

AUTHORS: Mitchell, D. T., & Snyder, S. L. (Eds.)

PUBLICATION INFORMATION: 1997

The University of Michigan Press
839 Greene Street, P.O. Box 1104
Ann Arbor, Michigan 48106-1104
E-Mail: umpress-www@umich.edu
http://www.press.umich.edu/

This edited book by Mitchell and Snyder seeks to introduce disability studies to the humanities by exploring how writers have used physical and cognitive disabilities in literature. The chapters explore how disability is seen in our culture in relation to "aberrance" and "normalcy," and explores the meanings of health, the construction of the body, citizenship, and morality in relation to disability. The authors present a variety of literary perspectives in two parts. Part I is "Representations in History," and chapters include such topics as "Constructions of Physical Disability in the Ancient Greek World: The Community Concept" by Martha Edwards; "Defining the Defective: Eugenics, Aesthetics, and Mass Culture in Early Twentieth-Century America" by Martin S. Pernick; and "Conspicuous Contribution and American Cultural Dilemmas: Telethon Rituals of Cleansing and Renewal" by Paul K. Longmore. Part II is "A History of Representations," and includes chapters such as "Feminotopias: The Pleasures of 'Deformity' in Mid-Eighteenth-Century England" by Felicity A. Nussbaum; "The 'Talking Cure' (Again): Gossip and the Paralyzed Patriarchy" by Jan Gordon; and Disabled Women as Powerful Women in Petry, Morrison, and Lorde: Revising Black Female Subjectivity" by Rosemarie Garland Thomson.

TITLE: Perspectives on disability (Second Edition)

AUTHOR: Nagler, M. (Ed.).

PUBLICATION INFORMATION: 1993

Health Markets Research
851 Moana Court
Palo Alto, CA 94306

In this second edition edited by Mark Nagler, he once again explores the meaning of disability in our society. Using an interdisciplinary perspective, he offers articles by sociologists, psychologists, therapists, and others to explore the ways in which disability is constructed and understood. The book includes a foreword by Evan Kemp Jr. and an

introduction by Nagler. He divides the book into the following sections: "What it means to be disabled," "Society and disability," "The family and disability," "Sexuality and disability," "Medical and psychological issues and disability," "Education, employment, social planning and disability," and "Legal and ethical issues and disability." The selections for this second edition are good, but there are not many articles relating to people with developmental disabilities. This is the one main weakness of this text.

TITLE: The ABC-CLIO companion to the disability rights movement

AUTHOR: Pelka, F.

PUBLICATION INFORMATION: 1997

ABC-CLIO, INC
130 Cremona Drive, P.O. Box 1911
Santa Barbara, CA 93116-1911
http://www.abc-clio.com/

This text is a general introduction to the disability rights movement and the people and court cases that support or challenge it. It includes entries on such people as Ed Roberts and Judy Heumann. The book is organized as a dictionary, and has references from every aspect of the disability rights movement, from court cases to famous people, to historical events and disability culture. It also includes a chronology, beginning with the founding of the American School for the Deaf in 1817 and concluding in 1996.

TITLE: Teaching sociology of disabilities

AUTHORS: Schlesinger, L., & Taub, D. (Eds.).

PUBLICATION INFORMATION: 1998

American Sociological Association (ASA) Teaching Resources
1722 N Street, N.W.
Washington, DC 20036
http://www.asanet.org

Teaching sociology of disabilities is a collection of syllabi and instructional materials on disability issues. It can be purchased by ASA members for $17.00 and by non-ASA members for $21.00. A copy can be downloaded from the ASA web site at no charge.

Amazon.com

This is a list of books we found on the web site Amazon.com, which is probably the most well known on-line bookstore. Their address is www.amazon.com. We found these books either under the heading "Disability Studies" or "Sociology of Disability," and have listed books that have recently been published or are to be published within the next year. We have not read these books, and therefore cannot attest to the content. We are basing this list only on titles.

Disability Studies: A Reader
Stuart Carruthers, Jim Sandu/Paperback/To be published in 1999

The Disability Reader: Social Science Perspective
Tom Shakespeare (Editor)/Hardcover and Softcover/To be published in June 1998

Sexuality and People with Intellectual Disability
Lydia Fegan, et al/Hardcover/Published 1997

Gender and Disability: Women's Experiences in the Middle East
Lina Abu-Habib/Paperback/Published 1997

Struggles for Inclusive Education: An Ethnographic Study (Disability, Human Rights and Society
Anastasia D. Vlachou/Paperback/Published 1997

Disability and Society: Emerging Issues and Insights (Longman Sociology Series)
Len Barton (Editor)/Paperback/Published 1996.

Beyond Disability: Towards an Enabling Society (Open University Set Book)
Gerald Hales (Editor)/Hardcover/Published 1996

The Sexual Politics of Disability: Untold Desires
Tom Shakespeare, et al/Hardcover/Published 1996

In Search of Freedom: How Persons with Disabilities Have Been Disenfranchised from the Mainstream of American Society
Willie V. Bryan/Paperback/Published 1996

Understanding Disability: From Theory to Practice
Michael Oliver/Paperback/Published 1996

Bad-Mouthing: The Language of Special Needs
Jenny Corbett/Hardcover/Paperback/Published 1995

Disabling Laws, Enabling Acts: Disability Rights in Britain and America (Law and Social Theory)
Caroline Gooding/Hardcover/Published 1995

Enforcing Normalcy: Disability, Deafness, and the Body
Lennard J. Davis/Paperback/Published 1995

The Eye of the Beholder: Deformity and Disability in the Graeco-Roman World
Robert Garland/Hardcover/Published 1995

Feminist Disability Studies

The books and articles selected for this section represent a recently recognized branch of disability studies: feminist disability studies. This field may have begun with British women such as Jenny Corbett and Jenny Morris, who take a feminist stance that the personal is political, and explore their lives as women with disabilities through this political lens. More recently, feminist scholarship in the United States has begun to explore disability studies within feminism. Scholars such as Rosemarie Garland Thomson call for feminist to recognize disability as a category of otherness, such as race, class, gender, and sexual orientation, and to locate feminist disability studies in the broader area of identity politics.

The selections here represent just some of the voices and perspectives in this relatively new and rapidly growing field. Many of these are also included in the information package, Women with Disabilities: Issues, Resources, Connections, Revised.

TITLE: Redrawing the boundaries of feminist disability studies

AUTHOR: Garland Thomson, R.

PUBLICATION INFORMATION: 1994

Feminist Disability Studies, 20(3), 583-597.

In this review essay, Rosemarie Garland Thomson argues for the recognition of feminist disability studies within feminism. She states that feminist critical analysis does not usually recognize disability as a category of otherness (as it does with race, class, and gender) unless the study specifically states this focus. Although helpful, she would like to see a shift away from women's autobiographical accounts of their own experiences with disability, which often promote the "disaster/terror/pity scenario of disability", to an articulation of feminist disability studies as a "major critical subgenre within feminism." She asserts that feminist disability studies can be located in the broader area of identity politics if discourses of the body marked as deviant are included.

To illustrate her argument, Thomson draws on four feminist works. The first three, Invalid women: Figuring feminine illness In American fiction and culture, 1840-1940 by Diane Price Herndl, Monstrous imagination by Marie-Helene Huet, and Tattoo, torture, mutilation, and adornment: The denaturalization of the body in cultural text edited by Frances E. Mascia-Lees and Patricia Sharpe, do not deal with "disability" specifically, instead, Thomson interprets these works in a feminist disability studies perspective. She uses the fourth book, Barbara Hillyer's Feminism and disability because it specifically addresses the issue of disability and feminism, and because it embodies the feminist principle that the personal is political. Thomson hopes that these four books introduce perspective into the emerging field of feminist disability studies.

TITLE: Feminism and disability

AUTHOR: Hillyer, B.

PUBLICATION INFORMATION: 1993

University of Oklahoma Press
1005 Asp Avenue
Norman, OK 73019-0445
http://www.ou.edu/oupress/

Written out of a need in the feminist movement to include women with disabilities and a need in the disability rights movement to address the unique experiences of women, Feminism and disability combines the personal, political, and intellectual aspects of feminist theory and disability theory. Hillyer discusses such issues as body awareness, community, nature and technology, and the ways in which cultural standards of language, independence, and even mother-blaming are constructed. She also challenges political movements which stress productivity and normalization in order to include more types of people and more aspects of the human condition.

TITLE: What happened to you? Writings by disabled women.

AUTHOR: Keith, L. (Ed.).

PUBLICATION INFORMATION: 1996

The New Press
450 West 41 Street
New York, NY 10036
http://www.wwnorton.com/newpress/welcome.htm

Lois Keith compiled collections of fiction, essays, and poetry by disabled women in her new book, What happened to you? Her goal is to give women with disabilities a space to express their views on such topics as abuse, equality, sexuality, prejudice, and legislation dealing with disability issues. These narratives construct disability as a cultural and political issue, not only as a personal one.

TITLE: Mustn't grumble: Writings by disabled women

AUTHOR: Keith, L. (Ed.).

PUBLICATION INFORMATION: 1994

The Women's Press
34 Great Sutton Street
London EC1 V0DX
ENGLAND
E-mail: jas@interbooks.com
http://www.the-womens-press.com/

This edited book, compiled by a woman with a disability, presents writings by other women who have a range of physical disabilities. The short stories and poems included in this book range in topic from issues of accessibility to abuse to equality. Disability is framed by these narratives as a social, cultural, and political issue, not only as a personal one. This is an excellent account of disability issues from a woman's perspective. It is powerful, moving, and educating for all readers.

TITLE: Does she boil eggs? Towards a feminist model of disability

AUTHOR: Lloyd, M.

PUBLICATION INFORMATION: 1992

Disability, Handicap & Society, 7(3), 207-221.

The author examines disability from the perspective of women with disabilities. She focuses on the social model of disability rather than a medical model and asserts that disability is another form of oppression experienced by women. She argues that disabled women have been excluded from both the women's movement, which is oriented toward non-disabled women, and from the disability rights movement, which is oriented toward disabled men. Using the history of black feminism, the author argues for a reframing of the analysis in which to explore the simultaneous experiences of gender and disability.

TITLE: Women and disability

AUTHOR: Lonsdale, S.

PUBLICATION INFORMATION: 1990

St. Martin's Press
175 Fifth Avenue
New York, NY 10010
http://www.stmartins.com/

Lonsdale explores how women with physical disabilities experience the double discrimination of being both a woman and a person with a disability in society. Placing physical disability in a social and political context rather than an individual one, she uncovers how women with disabilities have been rendered invisible, how they see their self image and body image, how physical disability often leads to dependence, and how women experience a loss of civil liberties and how they face discrimination. Lonsdale also considers the ways in which these situations can change for women, specifically, how policy practices can change so women can achieve greater independence. Chapters include subjects such as the social context of disability, invisible women, self-image and sexuality, employment, financial consequences of disability, discrimination, and independence.

TITLE: Feminism and disability

AUTHOR: Morris, J.

PUBLICATION INFORMATION: 1993

Feminist Review, 43, 57-70.

The author discusses the absence of women with disabilities from feminist scholarship and feminist theory. Morris claims that a significant failure of feminism is that it fails to incorporate disabled women into its politics, theory, research, and methodology. She argues that feminist theory would benefit from the inclusion of the concerns and experiences of disabled women, and that feminist theory and feminist methodology have major contributions to make to the disability research. The author discusses her anger and frustration with feminism in two ways: first, that disability is generally invisible from feminism's mainstream agenda, and second, that when disability is a subject of research by feminists, the researchers objectify disabled people so that the research is alienated from their experiences rather than attempting to understand the experiences of disabled women.

TITLE: Personal and political: A feminist perspective on researching physical disability

AUTHOR: Morris, J.

PUBLICATION INFORMATION: 1992

Disability, Handicap & Society, 7(2), 157-166.

Morris asserts that feminist theory and methodology have largely ignored and alienated women with disabilities and the research conducted by disabled people. She argues the feminist theory needs to take up the challenge of applying their principles to the study of disability and to examine the lives of disabled women. In turn, Morris feels that disabled women and disability research in general has much to learn from feminist methodology; mainly the principle of making the personal political. In addition, Morris outlines the role she sees for nondisabled researchers interested in researching disability-related issues. She views the role of the non disabled researcher as an ally, and calls on non disabled as well as disabled researchers to continue to study the ways in which the non disabled society oppresses its members with disabilities. Lastly, she argues that disability research is of great importance in the general understanding of the perpetuation of inequalities in society.

TITLE: Pride against prejudice

AUTHOR: Morris, J.

PUBLICATION INFORMATION: 1991

New Society Publishers
P.O. Box 189
1680 Peterson Rd.
Gabriola Island, BC V0R 1X0
CANADA
E-Mail: nsp@island.net
http://www.newsociety.com/

Morris, a disabled feminist and activist, provides a feminist analysis to the study of the experiences of women with disabilities. Basing her arguments on the feminist principle that the personal is political, Morris eloquently challenges such issues as prejudice, abortion, and the notion that people with disabilities lead lives that are not worth living. She further discusses the history of people with disabilities in institutions and under the Nazi regime. Morris also examines the meaning of disability in Western culture and the meanings of history of segregation, dependence, and an emerging independence of people

with disabilities. Pride against prejudice is a commentary on political activism and rights, and stresses the need to fight back against the prejudice, stereotypes, and oppression of an abelist culture.

TITLE: The lives of women with mental retardation: A multiple minority perspective

AUTHOR: Olson, D. L.

PUBLICATION INFORMATION: 1991

Unpublished doctoral dissertation
Syracuse University
Syracuse, NY 13244

This dissertation by Deborah Olson explores the lives of women labeled mentally retarded. She argues that this label, along with their gender, has placed these women in the disadvantageous position of being in a multiple minority group. Through in-depth interviews with five women labeled mentally retarded, Olson seeks to understand how they see themselves as women with mental retardation and how they interact with people who have impact on their lives. The major finding from this work is that women with a label of mental retardation are more prepared to handle disability discrimination than gender discrimination, and that the women's movement has not provided them with the awareness of choices it has provided for other women who do not have cognitive disabilities.

TITLE: Toward a feminist theory of disability

AUTHOR: Wendell, S.

PUBLICATION INFORMATION: 1997

In L. J. Davis (Ed.)., The disability studies reader (pp. 260-278). New York: Routledge.

Routledge
29 West 35th Street
New York, NY 10001
212-216-7800
FAX 212-564-7854
http://www.thomson.com/routledge

The author argues that disability is not a "biological given," rather it is a social construction of biological reality (like gender) and because of this, the fact that 16% of women have disabilities, and that feminist thinkers have raised the most radical issues concerning cultural attitudes to the body, a feminist theory of disability is needed. Wendell argues that those with disabilities are constructed as "the other" and because of this are seen as failing to control their bodies (control of our bodies is demanded by society) and as symbolizing the threat of pain, limitation, dependency, and death. She calls for people with disabilities and their knowledge and experience with their bodies to be fully integrated into society, and concludes that in this way bodies would be liberated.

TITLE: The rejected body: Feminist philosophical reflections on disability

AUTHOR: Wendell, S.

PUBLICATION INFORMATION: 1996

Routledge
29 West 35th Street
New York, NY 10001
212-216-7800
FAX 212-564-7854
http://www.thomson.com/routledge

In The rejected body, Susan Wendell, a woman with Chronic Fatigue Syndrome, draws parallels between her own experiences with illness to feminist theory and disability studies. She argues (as many others have), that feminist theory has neglected to incorporate the perspectives and experiences of women with disabilities, and that these perspectives must be included in future discussions of feminist ethics, the body, and the social critique of the medical model. Wendell also examines how cultural attitudes about the body contribute to disability oppression and society's unwillingness to accept different types of bodies.

Autobiographies/Personal Narratives

This section highlights some of the current autobiographies and personal narratives of people with disabilities. This is just a sampling, since the previous annotated bibliographies in this packet have presented a much more detailed list.

TITLE: Life as we know it: A father, family, and an exceptional child

AUTHOR: Bérubé, M.

PUBLICATION INFORMATION: 1996

Vintage Books
Random House, Inc.
Customer Service, Dept. #05001
Random House Distribution Center
400 Hahn Road
Westminster, MD 21157
E-Mail: customerservice@randomhouse.com
http://www.randomhouse.com/

This remarkable book is a father's story of the life of his 4-year-old son James, who has Down syndrome. It is far more than just a personal memoir of his son's birth and young life. In following the developmental stages, social experiences, and involvement with social services that James passes through, Bérubé explores their social implications, including such topics as IQ testing, the politics of education, disability law, social services, health care, and entitlements. Implicit in these discussions are not just his own family's experiences in these realms, but also concepts such as social justice, what it means to be human, and what kind of society is valued and by what means we determine this value.

TITLE: Body, remember

AUTHOR: Fries, K.

PUBLICATION INFORMATION: 1997

Plume
Penguin Putnam Inc.
375 Hudson Street
New York, NY 10014
http://www.penguin.com

In this memoir, Kenny Fries explores his life and experiences with his disability. Having been born with congenital deformities that affected the lower part of his body, Fries searches medical records, talks with family and friends, and examines past relationships in order to better understand his disability. In addition to an understanding of his physical body, Fires also explores his sexuality and personal relationships. This is a memoir about disability, but it is also about the discovery and understanding of his identity.

TITLE: Thinking in pictures: And other reports from my life

AUTHOR: Grandin, T.

PUBLICATION INFORMATION: 1995

Bantam Doubleday Dell Publishers Groups, Inc.
1540 Broadway
New York, NY 10036
E-Mail: webmaster@bdd.com
http://www.bdd.com/

Thinking in pictures is about the childhood and development of Temple Grandin, a woman with autism. She likens herself to the robotic character, Data, on the science fiction television program, Star Trek: The Next Generation. She says words are like a second language to her, noting that she thinks primarily in images. Grandin, who holds a Ph.D. in animal science and has designed equipment that revolutionized the livestock industry, proposes that genius and autism may sometimes be closely related.

TITLE: Moving violations: War zones, wheelchairs, and declarations of independence

AUTHOR: Hockenberry, J.

PUBLICATION INFORMATION: 1995

Hyperion
114 Fifth Avenue
New York, NY 10011

Moving violations is an honest and often humorous account of Hockenberry's life as a man with a disability. He takes the reader on a journey in which he reflects upon the events in his life, from the accident that, at age 19, caused a spinal cord injury to his work as a nationally renown broadcast journalist. He does not flinch at talking about the personal aspects of disability. And he shares the adventures of his career, such as riding a mule up a mountainside with Kurdish refugees who were being driven from their land by the Iraqis

after Desert Storm. Hockenberry also explains how his disability, rather than limiting him, is a window through which he frames his view of the world--how it expands his gaze and gives him insight that defines who he is and what he does.

TITLE: Bus girl: Poems by Gretchen Josephson

AUTHORS: Lubchenco, L. O., & Crocker, A. C.

PUBLICATION INFORMATION: 1997

Brookline Books
P.O. Box 1047
Cambridge, MA 02238
E-Mail: BROOKLINEBKS@delphi.com
http://people.delphi.com/brooklinebks/index.html

This book consists of 25 poems written by Gretchen Josephson, a woman with Down syndrome. She started writing poetry while still in her teens, when she began a job as a bus girl at a restaurant. Her poetry chronicles her life experiences with family, friends, love, and other areas of life. The editors have divided her poetry into sections, which include Bus Girl, Love for Always, Vacations and Travel, Family, Death and Greed, Faith, and Other Poems. Unlike other artistic works such as Musn't grumble edited by Lois Keith, Josephson does not write about disability. Instead, she simply creates poetry about her life.

TITLE: Waist-high in the world: A life among the disabled

AUTHOR: Mairs, N.

PUBLICATION INFORMATION: 1997

Beacon Press
25 Beacon Street
Boston, MA 02108
617-742-2100
E-Mail: lpemstein@beacon.org
http://www.uaa.org/Beacon/

Nancy Mairs, a brilliant essayist and poet who has authored six previous books, reflects upon her experiences as a woman with multiple sclerosis in Waist-high in the world. She discusses such topics as adjusting to change, reconciling body image, experiencing sexuality and pleasure, and seeking equality and justice. She also probes other disability issues, such as assisted suicide and selective abortion, and she revisits an article she once wrote for Glamour magazine that focused on young people with disabilities.

TITLE: The me in the mirror

AUTHOR: Panzarino, C

PUBLICATION INFORMATION: 1994

Seal Press
3131 Western Ave., Suite 410
Seattle, WA 98121-1041
E-Mail: sealprss@scn.org
http://www.sealpress.com/

Written by writer, disability activist, and artist Connie Panzarino, The me in the mirror is an autobiography of the life of this amazing woman. Born with Spinal Muscular Atrophy Type III, a rare disease, Panzarino describes her life as one of struggles and triumphs, and tells the stories of her relationships with her family, friends, lovers, her turn to lesbianism, and of her years of pioneering work in the disability rights movement. This book is a must read for anyone interested in understanding the experiences of women with physical disabilities.

TITLE: Nobody, nowhere: The extraordinary autobiography of an autistic

AUTHOR: Williams, D.

PUBLICATION INFORMATION: 1992

Avon Books
1350 Avenue of the Americas
New York, NY 10019
http://www.avonbooks.com/avon/about.html

Donna Williams, who was diagnosed with autism when in her mid 20s, wrote Nobody, nowhere in an attempt to understand herself and to explore how she fit into the world around her. She candidly describes the teasing and mistreatment she experienced at the hands of her family and her ability to use role-playing to interact with others. Williams said of her book, "This is a story of two battles, a battle to keep out 'the world' and a battle to join it. I have, throughout my private war, been a she, a you, a Donna, and finally, an I."

TITLE: Somebody somewhere: Breaking free from the world of autism

AUTHOR: Williams, D.

PUBLICATION INFORMATION: 1994

Times Books
Random House Trade Group
New York, NY
http://www.randomhouse.com/trade/

This autobiography by Donna Williams poignantly and defiantly illustrates her life and struggle with autism. She powerfully articulates her "awakening to the world" and how she fought for others to do the same. She presents her perspective of autism and reminds the readers that it is crucial that they seek to understand her perspective and the perspectives of others with autism rather that imposing their own notions onto someone else. She asserts that she has taken control of her autism, that it does not control her.

TITLE: Like colors to the blind

AUTHOR: Williams, D.

PUBLICATION INFORMATION: 1996

Times Books
Random House Trade Group
New York, NY
http://www.randomhouse.com/trade/

Like colors to the blind is Donna Williams' third book about her life as a person with autism. When she was diagnosed with autism at the age of 25, she wrote Nobody, nowhere as an attempt to explore her experiences as a person with autistic symptoms. In her sequel, Somebody, somewhere, she continued to analyze how role playing and ritualistic behavior helped her to cope with her environment, and how she was able to begin to replace these mechanisms with genuine interactions. This, her latest work, builds upon the last, addressing relationships and emotions. Williams describes her relationship with Ian, who became her best friend and eventually her husband.

TITLE: Women with disabilities: Found voices

AUTHORS: Willmuth, M., & Holcomb, L.

PUBLICATION INFORMATION: 1994

The Haworth Press, Inc.
10 Alice Street
Binghamton, NY 13904-1580
E-Mail: getinfo@haworthpressinc.com
http://www.haworthpressinc.com/

Written almost entirely by woman with disabilities, Women with disabilities: Found voices is a deeply personal and compelling discourse of the body, violence, sexuality, and disability. The authors offer a multicultural perspective which speaks frankly about their experiences. They discuss the abuses they have endured and explain how they have struggled with the issue of being a woman with a body that does not conform to the image that society values.

Movies and Documentaries

This section offers just a few of the many movies and documentaries which are related to the field of disability studies. We have highlighted a select few that reflect a variety of perspectives, and have listed many more (the more mainstream films). For descriptions of these films, we recommend the web site of the Office of Special Education at the University of Virginia, Individuals with Special Needs in Films. Their web address is:

http://curry.edschool.virginia.edu/go/cise/ose/information/film

Another web site to refer to is "Films Involving Disabilities." The web address is:

http://www.caravan.demon.co.uk

You may also want to check under a more general directory. For that, we recommend the Internet Movie Database. Its address is:

http://us.imdb.com

While we certainly would recommend many of these titles, we are not certain of the availability of all of them.

TITLE: Breathing lessons

DIRECTOR: Jessica Yu

PRODUCER: Inscrutable Films

DATE: 1996

35 minutes

The award-winning documentary, Breathing lessons, addresses what life as a person with a disability is like from the perspective of Mark O'Brien. O'Brien, who is a poet and journalist, is paralyzed and uses an iron lung. Through his poetry and his insightful commentary, he reflects on such issues as the meaning of life, death, sex, relationships, creativity, and religion.

TITLE: Brother's keeper

DIRECTORS: Joe Berlinger and Bruce Sinofski

PRODUCER: American Playhouse Theatrical Films

DATE: 1992

120 minutes

The lives of the Ward brothers, farmers in a rural community in upstate New York, are disrupted when the oldest brother, Bill, dies and his brother, Delbert, is accused of his murder. Brother's keeper focuses on the outpouring of support Delbert received from the community. To the townspeople, the Ward boys, as they were affectionately called--Bill, Delbert, Lyman, and Roscoe--were quiet men who lived in a run-down shack and farmed the land on which they grew up. The film chronicles the events surrounding Bill's death and Delbert's trial, including the townspeople's efforts to raise funds for Delbert's defense, their support of his innocence, and their refusal to see the Ward brothers through the lens of mental retardation.

TITLE: Self Advocates Becoming Empowered

PRODUCER: Act Video Products

DATE: 1997

20 minutes

Self Advocates Becoming Empowered is about people with cognitive disabilities forming a national organization to work on issues they deem important, such as closing institutions, exercising their rights as citizens, supporting people to live in communities, and opposing injustice in the criminal justice system. Likening their movement to the civil rights movement of the 60s, many of the advocates speak out about the importance of their mission to people with disabilities.

TITLE: Selling murder: The killing films of the Third Reich

DIRECTOR: Joanna Mack

WRITER AND RESEARCHER: Michael Burleigh

PRODUCER: Domino Films

DATE: 1991

This is a chilling Nazi propaganda film about the genocide of people with disabilities during the Second World War. Under what the Third Reich termed the "hereditary health law," they convinced doctors that killing people with mental or physical disabilities was for their own good, and the good of the Aryan nation at large. The original film makers used shadows and poor lighting to make people seem grotesque, and played on the medical model of disability in terms of what is "abnormal" and "normal," and even "human" and "not human." This is a powerful film that should generate interesting discussions if used in a disability studies class.

Please note: This film was aired on the Discovery Channel a few years ago, and we are not sure of its availability, but it is definitely worth a good search.

TITLE: Titicut follies

DIRECTOR: Frederick Wiseman

PRODUCER: Zipporah Films

DATE: 1967

83 minutes

Although more than 30 years old, Titicut follies remains a classic, depicting institutional life in a mental health facility. The 1967 Wiseman film is named for and centers around a talent show, the Titticut Follies, held for the inmates of the Bridgewater State Mental Hospital, in Massachusetts. While scenes from the talent show are disbursed throughout the film, the stark reality of daily life in the institution is revealed. There is little regard for the inmates' human dignity; not only is what they have to say dismissed, but they are subjected to strip searches, lack of privacy, ridicule, and isolation. Titticut Follies is a grim film that reflects the barren existence of life in a mental hospital.

TITLE: Vital signs: Crip culture talks back

DIRECTORS: David Mitchell and Sharon Snyder

PRODUCER: Studio Pulse Communication, Green Bay, WI

DATE: 1997

48 minutes

In the documentary Vital signs: Crip culture talks back, participants in a national Disability and the Arts conference explore the politics of disability through their performances, which include such texts as art, fiction, poetry, stand-up comedy, drama, and personal stories. It features such disability rights activists as Cheryl Marie Wade, Mary Duffy, and Harlan Hahn, and also includes group debates and behind-the-scenes conversations. The film also addresses the culture of disability and the shared struggle people with disability have in gaining access to influential cultural institutions.

TITLE: When Billy broke his head... and other tales of wonder.

DIRECTOR AND PRODUCER: Billy Golfus and David E. Simpson

WRITER AND NARRATOR: Billy Golfus

DATE: 1995

First premiering on PBS in 1995, this film by Billy Golfus explores the concept of disability rights and takes a close look at the disability rights movement and those involved. Golfus, who has a traumatic brain injury, intertwines his story with the experiences of others who are struggling for their rights. This is a must see.

TITLE: No apologies

PRODUCERS: Disabled Women's Theatre

DATE: 1994

This 28-minute video is by Wry Crips Disabled Women's Theatre, which is a comedy troupe of women who are at the forefront of the disability culture movement in the San Francisco Bay area. It is comprised of disabled and able-bodied women of diverse racial,

social, and class background. Wry Crips uses humor as a form of resistance. Their performances, comprised of poetry, readings, signing, performing skits, and reading narratives, all resist medical paradigms, social stereotypes, economic oppression, or individualist assumptions regarding disability issues. The women of Wry Crips embrace disability, seeing beauty and acceptance where able-bodied people only see difference and abnormality.

LIST OF MORE MAINSTREAM FILMS

Awakenings
Benny and Joon
The Big Parade
Born on the Fourth of July
Charly
Children of a Lesser God
Coming Home
Dominick and Eugene
The Elephant Man
Forrest Gump
Freaks
Gattaca
Mask
The Miracle Worker
My Left Foot
One Flew Over the Cuckoos Nest
Orphans of the Storm
Passion Fish
Rain Man
Skallagrig
Sling Blade
The Waterdance
What's Eating Gilbert Grape
Whose Life is it, Anyway?

Academic Programs

The following section offers a description of colleges and universities that offer classes, programs, or concentrations in Disability Studies. They range from academic institutions that offer classes representative of the Disability Studies perspective to institutions that offer advanced degrees in this field or related fields. For an overview of Disability Studies in general, please see "Disability Studies 101: From Werewolves to Hephaetus" by Joshua Harris Prager in The Wall Street Journal, August 31, 1998, and "Pioneering Field of Disability Studies Challenges Established Approaches and Attitudes," by Peter Monaghan, in The Chronicle of Higher Education, January 23, 1998.

Academic Institution:	Syracuse University
Program Name:	Disability Studies Concentration
Address:	Cultural Foundations of Education School of Education 805 South Crouse Avenue Syracuse, NY 13244-2280
Contact:	Steven J. Taylor, Ph.D. Coordinator, Disability Studies Concentration
Phone:	(315) 443-3851
E-Mail:	staylo01@mailbox.syr.edu
WWW:	http://soeweb.syr.edu/thechp/disstud.htm
Location on Campus:	Cultural Foundations of Education, School of Education
Program Description:	The Disability Studies concentration applies social, cultural, historical, and philosophical perspectives to the study of disability in society. Building on the tradition of Syracuse University's School of Education in the area of disability, the concentration is designed to help students understand and work to overcome the barriers to full participation of people with disabilities in community and society.

Consistent with the Syracuse tradition, this concentration stands at the forefront of change and new ways of thinking about and accommodating people with disabilities. While it adopts a cross-disability perspective, it devotes special attention to people who have been labeled as developmentally disabled or mentally retarded.

Program Emphasis:

As a graduate student pursuing this concentration, you will have a program of study that matches your own interests with the current activities of faculty and associates. Through course work, independent studies, thesis or dissertation research, or internships at the School of Education's disability centers and institutes, you will examine a range of issues confronting people with disabilities, including deinstitutionalization and community integration, current trends and controversies, advocacy and self-advocacy, the sociology of deviance and acceptance, community and family support services, media images of disability, gender and disability, and disability policy. In addition, you will be exposed to strategies for policy analysis, program evaluation, and community education. Depending on your interests and program of study, you will be encouraged to take courses both in the School of Education and other schools at Syracuse University, including the Maxwell School of Citizenship and Public Affairs, the Law School, and the School of Social Work.

Program Requirements:

Master of Science (M.S.)

- A minimum of 24 credits beyond the bachelor's degree and a thesis (3 or 6 credits) or a minimum of 30 credits beyond the bachelor's degree and a comprehensive examination.
- An internship (3 or 6 credits) at one of the School of Education's disability centers or institutes or another organization approved by the student's advisor.
- A minimum of 3 credits of qualitative or quantitative research methodology.

Doctor of Philosophy (Ph.D.)

- A minimum of 90 credits beyond the bachelor's degree; one-half of the credits, excluding dissertation hours, may be transferred from another university with the advisor's approval.

- A minimum of 12 credits of research methodology.
- A research apprenticeship (journal quality scholarly article) completed under the supervision of a faculty member.
- Qualifying examinations.
- An internship (6 to 12 credits) at one of the School of Education's disability centers or institutes or another organization approved by the student's advisor.
- Dissertation (typically, doctoral students register for 12-24 dissertation credits during the course of their studies).

Academic Institution:	Suffolk University
Program Name:	Master's of Public Administration/Disability Studies
Address:	Eight Ashburton Place Boston, MA 02108-2770
Contact:	Professor Richard Beinecke
Phone:	(617) 573-8062
E-Mail:	ssominfo@acad.suffolk.edu
Location on Campus:	Department of Public Management of the Frank Sawyer School of Management
Program Description:	Students take three semester credit courses, and also have independent studies, an internship, and a comparative policy course in Dublin and/or Puerto Rico.
Program Emphasis:	Policy Analysis and Public Management
Program Requirements:	Nine required MPA courses plus five additional courses required by the disability studies concentration. Three additional classes are also required.
Courses offered:	Disability Rights, Disability Issues, Disability and Public Policy, The U.S. Health System, Changes in Disability Policy

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Academic Institution:	University of Illinois at Chicago
Program Name:	Department of Disability and Human Development
Address:	Institute on Disability and Human Development 1640 West Roosevelt Road Chicago, IL 60516
Contact:	William J. Schiller Clinical Assistant Professor of Human Development
Phone:	(312) 413-1536
E-mail:	wjschill@uic.edu
WWW:	http://www.uic.edu/depts/idhd/idhdfull.html
Location on Campus:	College of Associated Health Professionals
Degree Programs:	Masters in Disability and Human Development Masters in Rehabilitation Technology Ph.D. program in Disability Studies jointly developed with the Department of Occupational Therapy and the Department of Physical Therapy. Post-doctoral research fellowships in the following areas: aging and disability, assistive technology, dual diagnosis, and policy analysis.
Program Description:	This interdisciplinary program provides students with experience and education in the College of Associated Health Professions, the School of Public Health, and the Colleges of Education, Engineering, Social Work, and the Department of Psychology. The program provides field experience through clinical programs in assistive technology, diagnostics, and mental health for people with mental retardation. Field-based internships are also available.
Program Emphasis:	Master's Program – emphasis in the newly proposed Department of Disability and Human Development, with specializations in Disability Studies, Rehabilitation Technology, and Disability Policy and Organization. PhD Program: The program has an interdisciplinary approach to the study of disability, examining the

social, political, biological, and cultural determinants of disability. The focus of student learning may include one of the following: a socio/cultural approach to disability, policy and practice, political and economic issues, vocational issues, family issues, and many more.

The DHD web site has extensive information, including program requirements and class listings for both the Master and Ph.D. programs. Please see the URL listed above for more information.

Academic Institution:	University of Maine, Orono
Program Name:	Interdisciplinary Disability Studies
Address:	115 Corbett Hall Orono, ME 04469
Contact:	Elizabeth DePoy
Phone:	(207) 581-1469
E-Mail:	liz_depoy@voyager.umeres.maine.edu
WWW:	http://cardinal.umeais.maine.edu/~cci/ccihi.html
Location on Campus:	Center for Community Inclusion
Program Description:	This program prepares both undergraduate and graduate students to be leaders in the field of developmental and related disabilities. It is a University-Affiliated Program (UAP) which provides an interdisciplinary education in the field of disability. The program offers practica, coursework, assistantships, and internships in university and community settings throughout the state, and is affiliated with other universities in Maine. The College of Education, in collaboration with the Center for Community Inclusion, offers a program that prepares students to aid people with disabilities in school-to-work transition. Many of these courses are interactive television courses, which allows people from all over Maine to enroll.

Program Emphasis:	Developmental Disabilities
Program Requirements:	Students can choose elective courses from departments such as Education, Communication Disorders, Human Development, Nursing, Psychology, Sociology, Public Administration, and Social Work. Practica also are available and are developed individually to meet the needs of students.
Degree Program:	Personnel Preparation Program for Transition Specialists
Courses Offered:	Developmental Disabilities Across the Lifespan Interdisciplinary Seminar in Developmental Disabilities (Intro and Advanced) Positive Approaches for Challenging Behavior

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Academic Institution:	Medaille College
Program Name:	Disability Studies Certificate
Address:	18 Agassiz Circle Buffalo, NY 14214
Phone:	(716) 884-3281
FAX:	(716) 292-1582
WWW:	http://www.medaille.edu/ds.html
Program Description:	Students may receive certificates in disability studies, approved by the State Education Department. A total of 33 credit hours are required.
Program Requirements:	Students must complete each course listed below and maintain a cumulative grade point average of at least 2.00. The last 12 credit hours must be completed at Medaille College and an application for the certificate must be filed in the Office of the Registar prior to registering for the last course.

Courses Offered:	HSV 100 - Introduction to Human Services Across the Life Span or CYS 100 - Introduction to Child and Youth Services CYS 280 - Understanding Multicultural and Diverse Populations HSV 120 - The Dynamics of Interviewing HSV 210 - Introduction to Disabilities HSV 211 - Introduction to Disability Law HSV 285 - Workshop in Major Disabilities HSV 301 - Program Planning and Administration HSV 377 - Field Experience II CYS 377 - Field Experience I (6 credits) SSC 200 - Human Relations WRT 175 - College Writing II

Academic Institution:	Hunter College of the City University of New York
Address:	695 Park Avenue New York, NY 10021
Phone:	(212) 772-5745
Contact:	Phyllis Rubenfeld or Simi Linton
E-Mail:	phyllis.rubenfeld@hunter.cuny.edu
Location on Campus:	Disabilities Studies Project
Program Description:	An undergraduate program in disability studies has been proposed for the 1998-1999 academic year. No further information is available.

Academic Institution:	The University of Leeds
Program Name:	MA/Diploma in Disability Studies and MA/Diploma in Disability Studies by Distance Learning
Address:	Leeds, LS2 9JT UNITED KINGDOM
Phone:	0113 233 4408
Fax:	0113 233 4415

WWW:	http://www.leeds.ac.uk/sociology/pgbroch.disabil.htm
Contact:	Colin Barnes, Director Debbie Westmoreland, Postgraduate Secretary
Location on Campus:	Department of Sociology and Social Policy
Program Description:	This advanced scheme of study is designed for people working or planning a career in the field of disability, and is especially suitable for service providers, practitioners and policy makers including: educational psychologists, educationalists in further and higher education, physiotherapists, occupational therapists, social workers, community nurses, doctors, architects, town planners etc. These courses can easily be fitted in with a busy working life. Students are required to attend the University only one afternoon or one evening a week over one or two years, depending on the option chosen. This unique and popular program of study provides students with an in-depth perspective on a wide range of disability related issues. It is offered on a modular basis, and each module is designed to give fresh insights into the concepts associated with disablement in modern society and will provide a basic grounding in the principles and theories upon which practice is based.
Program Emphasis:	Disability as an equal opportunities issue will be explored through the study of contemporary organizations and institutionalized practices. The course is designed to enable students to bridge the gap between theory and practice. For the Diploma in Disability Studies students are required to study four modules as follows: Module 1: Theories and definitions of disability Module 2: Social policy, politics and disabled people Module 3: Culture, researching disability and changing practice Module 4: Disability project

For the MA in Disability Studies students are required to study modules 1, 2, and 3 as for the Diploma in Disability Studies and two further modules described in more detail at the WWW site at the address listed above.

Information on the MA/Diploma in Disability Studies by Distance Learning can be viewed at
http://www.leeds.ac.uk/sociology/pgbroch.disabdl.htm

Academic Institution:	University of Hawai'i at Manoa
Program Name:	Pacific Partnerships in Disability and Diversity Studies
Address:	Center on Disability Studies University of Hawai`i at Manoa 1776 University Ave UA 4-6 Honolulu, HI 96815
Contact Person:	David Pfeiffer, Ph.D.
Phone:	(808) 956-9202
Fax:	(808) 956-3162
E-Mail:	pfeiffer@hawaii.edu
Program Description:	Beginning September 1998, the primary disability studies program at the University is the Pacific Partnerships in Disability and Diversity Studies, which prepares students to be leaders and researchers in areas pertaining to children and youth with disabilities. The program has a dual focus designed to increase leadership personnel to implement program improvement, and to infuse cultural competence in services for children and youth with disabilities. The program is an interdisciplinary approach, includes core seminars, research, and internship experiences. Key components of leadership development in disability studies and cultural diversity is faculty and student mentorship. Peer mentorship also will be fostered by linking "partner" doctoral students, based on professional and personal interests in Pacific cultures.

Other programs include Maternal and Child Health Leadership Education in Neurodevelopmental and Related Disability Programs, as well as more than 20 others relating to community outreach in the Pacific Rim, Hawaiian children with mental health problems, assistive technology, and other areas.

Journals and Magazines

TITLE:	Disability & Society
ADDRESSES:	
Subscriptions:	875-81 Massachusetts Avenue Cambridge, MA 02139
Submissions:	Professor Len Barton Disability & Society Division of Education University of Sheffield 388 Glossop Road Sheffield S10 2JA UNITED KINGDOM
PHONE:	1-800-354-1420
WWW:	http://www.carfax.co.uk/dso-ad.htm
SUBSCRIPTION RATES: (annually)	Institutional: $416 Individual: $118
FREQUENCY:	Published 5 times a year (February, April, June, September, and November)
AVAILABILITY:	Journal and on-line (with paid subscription)

Disability & Society is an international journal providing a focus for debate about such issues as human rights, discrimination, definitions, policy and practices. It appears against a background of change in the ways in which disability is viewed and managed.

Definitions of disability are more readily acknowledged to be relative; custodial approaches are seen as inadequate and unacceptable--placing greater emphasis on community care and integration. However, policy intentions may not have the desired effects on the realities of everyday practice and policy changes themselves may be merely cosmetic, or appropriate but unfunded.

While publishing articles that represent all the professional perspectives, the journal also provides an opportunity for the consumers of the services to speak for themselves.

TITLE:	Disability Studies Quarterly	
ADDRESSES:		
Subscriptions:	David Pfeiffer Center on Disability Studies University of Hawai'i at Manoa 1776 University Avenue, UA-4-6 Honolulu, HI 96822	
Submissions:	Every article published in the Quarterly is invited and reviewed by the editor or special editor. A call for manuscripts on specific topics is usually announced in each issue. Contributions or suggestions can be sent to David Pfeiffer at the address above.	
SUBSCRIPTION RATES*: (Annually)	Institutional Individual SDS member Student Low-income (* Subscription is not included in membership)	$45 $35 $30 $20 Whatever is affordable
FREQUENCY:	Published 4 times a year by the Society for Disability Studies.	
AVAILABILITY:	Journal, diskette, or via e-mail.	

The Disability Studies Quarterly is a multidisciplinary and international journal of interest to social scientists, scholars in the humanities, disability rights advocates, and others concerned with the problems of people with disabilities. The purpose of the Quarterly is to provide a place where people from diverse backgrounds can share ideas and to engage in dialogues that cut across disciplinary backgrounds and substantive concerns. The Quarterly is committed to developing theoretical and practical knowledge about disability and to promoting the full and equal participation of persons with disabilities in society.

TITLE: Journal The Association Of Persons With Severe Handicaps (JASH)

ADDRESSES:

Subscriptions:
29 W. Susquehanna Avenue
Suite 210
Baltimore, MD 21204
(410) 828-8274
FAX (410) 828-6706

Submissions:
Lori Goetz, Editor
JASH Editorial Offices
Department of Special Education & Communicative Disorders
San Francisco University
1600 Holloway Avenue
San Francisco, CA 94132
(415) 338-1306

SUBSCRIPTION RATES*: (Annually)

Agency or library	$190
General	$ 85
Student or parent	$ 45

* Membership in TASH includes the journal; see membership information under "ORGANIZATIONS"

FREQUENCY: Published quarterly

The Journal of The Association for Persons with Severe Handicaps (JASH) is a quarterly journal published by TASH (formerly The Association for Persons with Severe Handicaps), that emphasizes articles that report original research, authoritative and comprehensive reviews, conceptual and practical positions papers that offer new directions, and effective assessment and intervention methodologies and service delivery model program descriptions.

TITLE: Journal of Disability Policy Studies

ADDRESSES:

Subscriptions:
Department of Rehabilitation, Education, and Research
University of Arkansas
346 N. West Avenue
Fayette, AR 72701

Submissions:	Kay Fletcher Schriner, Ph.D., Editor Department of Rehabilitation, Education, and Research University of Arkansas 346 N. West Avenue Fayette, AR 72701
PHONE:	(501) 575-3656
FAX:	(501) 575-3253
SUBSCRIPTION RATES: (Annually)	Individual and institutional $24 Additional $5.00 charge for international subscriptions
FREQUENCY:	Published quarterly.
AVAILABILITY:	Journal, tape, or diskette.

The Journal of Disability Policy Studies addresses a broad range of topics on disability policy from the perspectives of a variety of academic disciplines and publishes articles pertaining to both macro-policy issues (such as the social constructions which direct and constrain policymakers) and micro-policy issues (such as legislative remedies and regulatory matters).

TITLE:	Mental Retardation
ADDRESSES:	
Subscriptions:	AAMR 444 North Capitol Street, NW Suite 846 Washington, DC 20001-1512 (202) 387-1968 or 1-800-424-3688 FAX (202) 387-2193
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SUBSCRIPTION RATES:	1 year	$ 95
	2 years	$170
	3 years	$255
	Single issue	$ 30
	Additions:	
	For Canada	$ 6
	Overseas	$ 15

FREQUENCY: Bi-monthly

Mental Retardation (MR) is a journal of policy, practices, and perspectives in the field of mental retardation. As a journal with an applied focus, MR publishes essays, qualitative and quantitative research articles, conceptual papers, comprehensive reviews, case studies, policy analyses, and innovative practice descriptions and evaluations. The style, methodology, or focus of an article is less important than its quality and contribution to our knowledge.

TITLE: Mouth

ADDRESS: 61 Brighton Street
Rochester, NY 14607-2656

FAX: 716-442-2916

SUBSCRIPTION RATES:

(Annually)	Organization/school/hospital:	$48
	Personal subscription + 1 "hardship" subscription:	$32
	Person with a disability or family member:	$16
	"Hardship" subscription	$ 2
	"Recovering Professional" (personal plus 2 hardship subscriptions)	$48
	Outside US add $7.00 USD	

FREQUENCY: Published 6 times a year

AVAILABILITY: Magazine, large print, round-trip audiocassette.

This thought-provoking magazine features investigative journalism, news, and interviews with disability rights activists, reserving some of its harshest criticism for the "helping professions." Mouth also publishes poetry and essays written by people with disabilities, and does not include commercial advertisements.

TITLE:	The Ragged Edge (formerly The Disability Rag)	
ADDRESS:	The Advocado Press P.O. Box 145 Louisville, KY 40201	
SUBSCRIPTION RATES: (Annually)	Organization Individual International	$35.00 $17.50 $42.00
FREQUENCY:	Published 6 times a year	
AVAILABILITY:	Magazine, on-line at: http://www.ragged-edge-mag.com/index.shtml#edge	

Ragged Edge is successor to the award-winning periodical, The Disability Rag. In Ragged Edge, and on their web site, you'll find the best in today's writing about society's "ragged edge" issues: medical rationing, genetic discrimination, assisted suicide, long-term care, attendant services. They cover the disability experience in America--what it means to be a crip living at the end of the 20th century.

ORGANIZATIONS

Association on Higher Education and Disability (AHEAD)
P.O. Box 21192
Columbus, OH 43221-0192
E-Mail: ahead@postbox.acs.ohio-state.edu
http://www.ahead.org/index.htm

AHEAD is an international organization of professionals committed to the full participation of individuals with disabilities in higher education. The Association provides programs, workshops, publications, and conferences that promote "excellence through education, communication and training."

MEMBERSHIP FEES:	Institutional	$250
	Active professional	$100
	Additional professional (addendum to institutional membership with voting rights)	$ 65
	Paraprofessional (Student)	$ 50

Center for Disability Studies
Hawai'i University Affiliated Program
University of Hawai'i at Manoa
1776 University Avenue, UA-4-6
Honolulu, HI 96822
(808) 956-4454
http://www2.hawaii.edu/~huap/

The Hawaii University Affiliated Program (UAP) was established in 1988 as part of a network of more than 60 UAPs in the United States. UAPs were first developed in the 1960s in response to the Developmental Disabilities Act to provide training, research, and services for improved quality of life for persons with disabilities. The Center for Disabilities Studies activities extend throughout the state and region with more than 25 funded projects in five initiative areas: Mental Health, Special Health Needs, Pacific Outreach, Transition/Supported Employment , and School and Community Inclusion. The Center also serves as the editorial office of the Disability Studies Quarterly.

Center for Health Policy Research
The Center the Study and Advancement of Disability Policy
George Washington University
2175 K Street, N.W., Suite 700
Washington, DC 20037
(202) 496-8452 V/TTY
FAX: (202) 467-2251
E-Mail: ihorxs@gwumc.edu
http://www.gwumc.edu/chpr/

The Center for Health Policy Research conducts research and analysis of public policy issues that affect persons with disabilities and their families. It also provides public education, leadership development and training, technical assistance and information dissemination to disability groups and others interested in learning about issues pertaining to people with disabilities. The focus of the Center is on projects that foster the inclusion, integration, and empowerment of individuals with disabilities and their families.

Disability Research Unit
Department of Sociology and Social Policy
The University of Leeds
Leeds, LS2 9JT
UNITED KINGDOM
+44 113.233.4414
Fax +44 113.233.4415
E-Mail: disability-research-request@mailbase.ac.uk
http://www.leeds.ac.uk/sociology/dru/dru.htm

The approach of the DRU to research is grounded in social model approaches which recognizes that disability is above all a form of institutional discrimination and social exclusion, rather than a product of physical difference between individuals. The DRU has been at the forefront of promoting this approach amongst the international research community.

The DRU seeks to adopt "committed" and "emancipatory" methods in all research projects. This is achieved wherever possible by devolving control over the production and dissemination of research--to individual research participants and to democratic organizations controlled by people with disabilities.

National Council on Disability
1331 F Street, N.W., Suite 1050
Washington, DC 20004
(202) 272-2004
TTY: (202) 272-2074
FAX: (202) 272-2022
E-Mail: mquigley@ncd.gov
http://www.ncd.gov/

The National Council on Disability (NDC) is an independent federal agency that "promotes policies, programs, practices, and procedures that guarantee equal opportunity for all individuals with disabilities, regardless of the nature of severity of the disability; and to empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society."

National Resource Center on Supported Living and Inclusion
Center on Human Policy
Syracuse University
805 South Crouse Avenue
Syracuse, New York 13244-2280
(315) 443-3851
TTY: (315) 443-4355
FAX: (315) 443-4338
Toll free: 1-800-894-0822
E-Mail: thechp@sued.syr.edu
http://soeweb.syr.edu/thechp/nrc.htm

The National Resource Center produces a range of informational materials on community integration. The Center continues to identify and document innovative approaches to help people with developmental disabilities participate in the community, and is especially interested in home ownership approaches, self-directed personal assistance, inclusive social-recreational programs, individualized funding streams, and strategies to meet the needs of culturally diverse groups.

Society for Disability Studies
c/o Robert Scotch
School of Social Science
University of Texas
Box 830688, Mail Station GR3.1
Richardson, TX 75083-0688
(972) 883-4122
FAX: (972) 883-2735
http://www.wipd.com/sds/

The Society for Disability Studies is a not-for-profit scientific and educational organization composed of social scientists, scholars in the humanities, disability rights advocates, and providers of services for persons with disabilities. Its stated purpose is "to bring together people from diverse backgrounds to share ideas and to engage in dialogues that cut across disciplinary backgrounds and substantive concerns. SDS is committed to developing theoretical and practical knowledge about disability and to promoting the full and equal participation of persons with disabilities in society."

MEMBERSHIP FEES (based on income):

Less than $15,000	$15
$15,000 - $30,000	$25
$30,000 - $45,000	$35
Over $45,000	$45

TASH (formerly The Association for Persons with Severe Handicaps)
Suite 210
Baltimore, MD 21204
410-828-8274
FAX: 410-828-6706
E-Mail: info@tash.org
http://www.tash.org/

TASH is an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field. TASH actively promotes the full inclusion and participation of persons with disabilities in all aspects of life.

Membership in TASH includes the Journal of The Association for Persons with Severe Handicaps, the TASH Newsletter, and reduced rates for the annual conference.

INTERNET RESOURCES

TITLE:	Disability Studies Forum
SPONSORED BY:	Centre for Psychotherapeutic Studies, University of Sheffield, United Kingdom
PURPOSE:	This forum addresses the social construction of disability and examines both the limitations and abilities of persons with disabilities. The group discusses therapeutic work, self-help and social forms of empowerment and other ways of circumventing societal barriers encountered by persons with disabilities.
ACCESS INFORMATION:	Send e-mail message to: listserv@maelstrom.stjohns.edu In body of message, type "sub DISABLED."

TITLE:	Disability Studies Web Ring
SPONSORED BY:	Canadian Centre on Disability Studies
PURPOSE:	This Web Ring was created to bring together web sites that are related to the field of Disability Studies, which examines the history, perspectives, culture, literature, sociology and experience of people with disabilities.
ACCESS INFORMATION:	http://www.escape.ca/~ccds/webring.html

TITLE:	Disability Social History Project
PURPOSE:	This site looks at the role people with disabilities have played in history, how they have been treated throughout time, and significant events in the history of disability civil rights. An electronic mailing list is also available.
ACCESS INFORMATION:	http://www.disabilityhistory.org/dshp.html E-Mail: sdias@disabilityhistory.org or pchad@disabilityhistory.org

MEMBERSHIP FEES:

Contributing member	$200
Agency, business or educational institution	$190
Individual	$ 85
Parent (non-professional), student, or paraprofessional	$ 45
Family (group rate)	$ 90

World Institute on Disability
510-16th Street, Suite 100
Oakland, CA 94612-1500
(510) 763-4100
TTY: (510) 208-9496
FAX: (510) 763-4109
E-Mail: webmail@wid.org
http://www.igc.org/wid

The World Institute on Disability is a non-profit public policy center dedicated to the promotion of independence and full inclusion in society of people with disabilities. Founded in 1983 by leaders of the Independent Living/Civil Rights Movement for people with disabilities, WID is committed to bringing policy into action.

Over the past 13 years, WID has earned an excellent reputation for high quality research and public education on a wide range of issues that impact people with disabilities. WID's board and staff includes experts in the fields of public policy, research, law, non-profit management, education, training, development, and business. More than half of the board and staff are people with disabilities. This enables WID to bring a cross-disability perspective to the policy arena. WID's innovative personnel policies are national models of affordable reasonable accommodation for people with disabilities, including personal assistance, adaptive technology, flexible work scheduling and telecommuting options.

TITLE: Disability Information for Students and Professionals

ACCESS INFORMATION: http://www.abilityinfo.com

This web site seeks to be a one-stop resource for students from around the world who wish to support and work with individuals with disabilities. This site also is intended for professionals within the field to continue in their knowledge. Includes daily news, job postings, a bulletin board area, more than 250 links, and live chat.

TITLE: Canadian Centre on Disability Studies

SPONSOR: University of Manitoba
Winnipeg, Manitoba

ACCESS INFORMATION: http://www.escape.ca/~ccds/

The Canadian Centre on Disability Studies is a consumer-directed, university-affiliated centre involved in research and education on disability issues. The CCDS is committed to fostering a spirit of collaboration between the disability and academic communities and other interested parties on initiatives of mutual interest and benefit nationally and internationally.

TITLE: Disability-Research Discussion List

SPONSOR: Disability Research Unit,
University of Leeds

ACCESS INFORMATION: You can join the list by sending the following message to mailbase@mailbase.ac.uk: join disability-research your name

This is an international e-mail discussion list administered at the DRU by Mark Priestley. The list (started in December 1994) is the largest of its kind in the world, and provides a forum for discussion on all aspects of disability research--both theoretical and practical.

The list is intended for all those interested in research as it affects disabled people both in the UK and internationally. It provides a forum for the exchange of ideas, information and news, particularly among researchers working within a social model of disability.

The list provides an opportunity for researchers, students and disabled people to share their ideas, experiences and research findings. It is also an excellent place to ask questions or seek information.

REPRINT

DISABILITY STUDIES AND MENTAL RETARDATION
By Steve Taylor

AND

SELECTED ANNOTATED BIBLIOGRAPHY ON DISABILITY STUDIES AND MENTAL RETARDATION
By Steve Taylor and Perri Harris

Reprinted from Disability Studies Quarterly, 16(3), 4-13.

Current Research

Disability Studies and Mental Retardation

Steve Taylor
Center on Human Policy
Syracuse University

People tagged with the label of mental retardation – or, if you prefer, cognitive, intellectual, or developmental disability – have been major targets of social prejudice and discrimination in Western societies. Forced segregation, state sanctioned abuse and dehumanization, status degradation and public mortification, involuntary sterilization, denial of fundamental rights, and even euthanasia occupy prominent roles in the history of mental retardation. No one can deny that people labeled mentally retarded have endured many harms at the hands of the nondisabled majority.

Yet those interested in understanding the social phenomenon known as mental retardation and reversing the historical pattern have yet to find a comfortable intellectual and academic home. On the one hand, special education, vocational rehabilitation, and other helping professions are dedicated to treating or "fixing" what is presumably wrong with the mentally retarded. Even humanistic approaches in these fields are based on a belief in the objective existence of mental retardation. On the other hand, it has not always been clear whether people labeled mentally retarded can fit under the broad umbrella of the disability rights movement and Disability Studies as an area of inquiry.

In this brief article, I argue that the study of mental retardation, as a social and cultural construct, belongs in Disability Studies and demonstrate how many of the principles associated with Disability Studies can be applied to the study of mental retardation. At the conclusion of this article, there is an annotated bibliography of selected books and articles that can serve as a foundation for inquiries in this area.

The perspectives and experiences of people labeled mentally retarded must provide a starting point for all research and inquiries in the study of mental retardation. Consistent with a Disability Studies perspective, studies must focus on how people tagged as mentally retarded view and experience their worlds. In contrast to people with disabilities such as deafness, blindness, or mobility impairments, many of those labeled mentally retarded cannot easily communicate their views. From a Disability Studies perspective, this becomes a problem to be solved – how can we understand their subjective experience? – rather than grounds for dismissing their points of view.

Mental retardation is a social construct and cultural artifact. This is not the place to provide a critical review of efforts to measure the illusive concept we call intelligence or to explain how mental retardation has been reified. Selections in the following annotated bibliography address these issues in depth. Suffice to say: of course, there are differences among people in intellectual ability, but this does not prove the objective existence of the construct of mental retardation or the utility of dividing humanity into two groups – the retarded and non-retarded. Who is or is not considered mentally retarded hinges on arbitrary and professionally controlled definitions and classification procedures. The construct of mental retardation exists in the minds of those who label other persons, and

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not those so labeled.

People labeled mentally retarded represent a minority group. The category of people labeled mentally retarded represent an historically powerless and discriminated-against minority group. The minority group model associated with Disability Studies generally (Hahn, 1987; Linton, 1994) applies equally well to people with this label.

That said, the concepts of a disability culture and a disabled identity are foreign to people labeled mentally retarded. If the starting point for inquiries into the disability experience is the point of view of disabled persons themselves, then we must take seriously the perspectives of people defined as mentally retarded. For people labeled as mentally retarded, the concept of culture carries negative meanings. One meaning associated with culture is the professional construct of cultural-familial retardation, a construct rooted in the Eugenics movement and used to justify sterilization and other policies designed to prevent the spread of feeblemindedness.

Another meaning of culture is Goffman's (1961) notion of the subterranean life of inmates of total institutions. In this latter sense, people labeled retarded may be said to share a distinctive culture to the extent that they have been forcibly removed from their families and communities and subjected to the routines of various forms of total institutions and human service settings.

Whereas many leaders of the disability rights movement claim pride in an identity as a disabled person, representatives of the growing "self-advocacy" movement reject the mentally retarded tag and insist on being defined as "people first." What draws people labeled mentally retarded together is a recognition of their oppression and determination to oppose how they have been defined and treated in society. Coming together represents an affirmation and celebration of common humanity.

The important role that family members play in the lives of people labeled mentally retarded must be recognized. For various reasons, some legitimate and some not, parents and other family members are influential in the lives of children and adults labeled mentally retarded. Scholarship in this area includes inquiries into the views and experiences of families of people with the mental retardation label. It should go without saying that the voices of family members cannot be regarded as a substitute for the voices of labeled people themselves.

Inquiries into the social, cultural, political, and economic situation of people labeled mentally retarded must be grounded in concepts and philosophies associated with Disability Studies generally. The classics and the heroes guiding Disability Studies can also guide those wishing to understand and change the situation of people labeled mentally retarded. The point of studies in this area is not to establish a separate field of inquiry, but to explore how people labeled mentally retarded can be included in broader discussions of such issues as disability, gender, race, culture, and class.

This raises the interesting and challenging question of who should speak for people labeled mentally retarded in academic and scholarly circles. Should the voices of members of other groups who have faced societal prejudice and discrimination be privileged? Or should we listen to parents and family members of people labeled mentally retarded and especially those defined as severely disabled? Should long-term allies and advocates of people defined as mentally retarded lead the way? Each of these groups can play an important role in studies in this area.

Consistent with a Disability Studies

perspective, however, people labeled mentally retarded must be permitted to speak for themselves. The culture of academe, with its emphasis on literacy and intellectual skills, poses obstacles to the participation of people so labeled in research and training in this area. A culture that evaluates students by their SAT or GRE scores hardly presents a welcoming environment for those with a substandard IQ. Herein lies the challenge for those of us concerned with understanding this social cultural phenomenon. We must find creative ways of involving people labeled mentally retarded in our work, whether through oral histories and autobiographies, jointly authored articles, guest lectures and presentations, or professional staff appointments at research and training centers.

Above all, we must stay close to the reality and experience of those we seek to understand.

References

Goffman, E. (1961). Asylums. Garden City, NY: Doubleday.

Hahn, H. (1987). Advertising the acceptably employable image: Disability and capitalism. Policy Studies Journal, 15, 551-570.

Linton, S. (1994). Disability studies vs. Disability policy studies. Disability Studies Quarterly, 14(2), 23-26.

Bibliography

Selected Annotated Bibliography on Disability Studies and Mental Retardation

Compiled by Steve Taylor and Perri Harris

History

Blatt, B., & Kaplan, F. (1974). Christmas in purgatory: A photographic essay on mental retardation. Syracuse, NY: Human Policy Press.

This is a reprinted edition of Blatt and Kaplan's 1966 photographic expose of conditions in America's institutions. Shot with a hidden camera, Christmas in Purgatory depicts overcrowded and dehumanizing conditions found at eight institutions in the Northeast. Blatt was one of the few professionals to speak out against institutional warehousing in the 1960s.

Bogdan, R. (1988). Freak show: Presenting human oddities for amusement and profit. Chicago: University of Chicago Press.

A social history of the depiction of "human oddities," including people with disabilities, for amusement and profit. Freak Show is a classic study of depictions of disability in popular culture.

Ferguson, P. M. (1992). Abandoned to their fate: Social policy and practice toward severely retarded people in America, 1820-1920. Philadelphia: Temple University Press.

A historical study of social policy and practice toward people labeled "idiots" or "severely retarded." Ferguson examines the problem of "chronicity" and shows how people with the most severe disabilities have been and continue to be excluded from reform movements.

Gelb, S. A. (1995). The beast in man: Degenerationism and mental retardation, 1900-1920. Mental Retardation, 33(1), 1-9.

Gelb describes the chain of scientific and theological reasoning that led to the perception of people with mental retardation as a social menace prior to the eugenics movement around the turn of the 20th century. According to degenerationism, the "feebleminded" formed a missing link between humans and lower species.

Gould, S. J. (1981). The mismeasure of man. New York: W. W. Norton & Co.

This is a history of attempts to define and measure the illusive concept of intelligence. Gould does a masterful job of demonstrating the ideological assumptions underlying psychological science.

Smith, J. D. (1985). Minds made feeble: The myth and legacy of the Kallikaks. Austin, TX: PRO-ED.

Debunking Goddard's infamous Kallikak study that purported to show the hereditary transmission of "feeblemindedness," Smith traces members of the Kallikak family and demonstrates how facts were twisted by the eugenicists to prove their theories.

Trent, J. W. (1994). Inventing the feeble mind: A history of mental retardation in the United States. Berkeley: University of California Press.

A sobering historical analysis of institutions and mental retardation. Arguing from a political economy perspective, Trent locates the source of abuse of people with mental retardation in the tendency to equate moral worth with economic productivity.

Wolfensberger, W. (1975). The origin and nature of our institutional models (Rev. Ed.). Syracuse, NY: Human Policy Press.

This is an analysis of the development of, and growth in, institutions in the 19th and 20th centuries. The book examines institutionalization in terms and philosophies of leaders in the field of mental retardation. This book contains the foundations for Wolfensberger's influential writings about "normalization" (now called social role valorization).

Theory

Biklen, D. (1988). The myth of clinical judgment. Journal of Social Issues, 44(1), 127-140.

This article challenges the primacy of professional decision-making and argues that clinical decisions are influenced by other factors such as economics, bureaucratic exigency, politics, service traditions, and societal prejudice.

Bogdan, R., & Biklen, D. (1977). Handicapism. Social Policy, 7(4), 14-19.

The authors introduce the concept of handicapism as a way to understand disability as a social construct. They define it as a "set of assumptions and practices that promote the differential and unequal treatment of people because of apparent or assumed physical, mental, - or behavioral differences." Handicapism results in prejudice, stereotypes, and discrimination.

Dexter, L. (1994). On the politics and sociology of stupidity in our society. Mental Retardation, 32, 152-155.

This is a reprint of an article originally published in the early 1960s. Dexter offers on of the first discussions of the social meaning of mental retardation. Using labeling theory and a social constructionist approach, he argues that traditional notions of mental retardation and intelligence need to be more critically examined.

Nibert, D. (1995). The political economy of developmental disability. Critical Sociology, 21(1), 59-80.

The article outlines the history of the treatment of people with disabilities from a historic materialist perspective. Framing his discussion around issues of political economy, the author argues that the experiences of people with disabilities, from work to cultural devaluation, stems from the political and economic context. He further asserts that exclusion of people with disabilities from the labor force and society, and by making them scapegoats for economic and social problems, have served to legitimate 20th century American capitalism.

Social and Cultural Studies

Bercovici, S. (1983). Barriers to normalization. Baltimore: University Park Press.

Focusing on people with mental retardation living in seven residential care facilities, Bercovici discusses how the human service system employs practices that promote dependency, passivity, fear, and incompetence for the people receiving these services. She links these problems to the larger service delivery system and to a dominant culture that oppresses and controls a subordinate group's aspirations to achieve a normal life style.

Bogdan, R., & Taylor, S. J. (1989). Relationships with severely disabled people: The social construction of humanness. Social Problems, 36, 135-148.

The authors discuss how nondisabled people define their caring and accepting relationships with people with severe disabilities. The authors frame their discussion around a sociology of acceptance and identify four dimensions which maintain humanness of the people with severe disabilities: attributing thinking to the other, seeing individuality in the other, viewing the other as reciprocating, and defining social place for the other.

Bogdan, R., & Taylor, S. J. (1994). The social meaning of mental retardation: Two life stories. New York: Teachers College Press.

The concept of mental retardation is challenged through life histories based on in-depth interviews with former inmates of institutions for people labeled retarded. The authors argue that mental retardation is not a real entity, but rather a social construction.

Edgerton, R. B. (1993). The cloak of competence: Revised and updated. Berkeley: University of California Press.

This updated edition of a classic ethnography in mental retardation focuses on former inmates of institutions for people with mental retardation. The author addresses stigma, passing, and the role for normal benefactors.

Edgerton, R., & Gaston, M. A. (Eds.) (1991). "I've seen it all!": Lives of older persons with mental retardation in the community. Baltimore: Paul H. Brookes Publishing Co.

The authors offer life histories of nine elderly people who have lived independently in the community for at least thirty years. These qualitative studies are based on participant observation and highlight each person's background, family history, institutional experience, and community life.

Ferguson, P. M., Ferguson, D. L., & Taylor, S. J. (Eds.) (1992). Interpreting disability: A qualitative reader. New York: Teachers College Press.

A compilation of qualitative and interpretive studies of people with disabilities or their families. The chapters are divided into four parts: disability at the edges of life, disability and the schools, disability and the community, and disability and culture.

Goode, D. (1994). A world without words: The social construction of children born deaf and blind. Philadelphia: Temple University Press.

Based on his study of two girls who were born with rubella and are deaf-blind and mentally retarded, Goode argues that despite a use of formal language, human beings can communicate and be understood through other means. He shows how the children created their own set of symbols to construct their reality using senses other sight and sound.

Goode, D. (1992). Who is Bobby? Ideology and method in the discovery of a Down Syndrome person's competence. In P. M. Ferguson, D. L. Ferguson, & S. J. Taylor (Eds.), Interpreting disability: A qualitative reader (pp. 197-212). New York: Teachers

College Press.

Goode uses an "emic" approach to the study of people with developmental disabilities. This approach is contrasted with typical "etic" or medical/objective approach. An emic approach is a subjective or insider point of view that may offer a better understanding of the competency of a person with a developmental disability.

Groce, N. (1992). "The town fool." An oral history of a mentally retarded individual in small town society. In P. M. Ferguson, D. L. Ferguson, & S. J. Taylor (Eds.), Interpreting disability: A qualitative reader (pp. 175-196). New York: Teachers College Press.

Groce explores the life of Millard Fillmore Hathaway, an individual labeled mentally retarded who lived in a small northeastern town in the late 19th and early 20th centuries. Groce reports that villagers categorized Millard as the town fool, although he was an accepted part of the community.

Langness, L. L., & Levine, H. G. (Eds.) (1986). Culture and retardation. Dordrecht, Holland: Reidel.

This compilation of ethnographic articles focus on the life experiences of people labeled mildly mentally retarded. They stress that mental retardation is more of a socio-cultural phenomenon than a medical/psychological one. The articles cover the subjects' lives in terms of their childhood, patterns of adapting to everyday life, and their response to the label of retardation. In addition, the editors offer a discussion about life history research of people labeled mentally retarded, as well as a discussion about anthropological contributions to this type of study.

MacEachen, E., & Mumby. H. (1996). Developmentally disabled adults in community living: The significance of personal control. Qualitative Health Research, 6, 71-89.

The authors explore issues in community living from the perspective of people with mild developmental disabilities. Participants report imposed control by service providers and isolation from the community. Most important, they wanted to be independent and in control of their own lives.

Mercer, J. (1973). Labeling the mentally retarded. Berkeley: University of California Press.

Based on an 8 year study that used IQ tests to screen 7,000 people for mental retardation, Mercer discovers that schools label people mentally retarded more than any other institution, that minorities are over-represented in the category of mental retardation, and that after leaving school most people are no longer included in this category. Mercer examines the social and cultural aspects of being labeled mentally retarded, but does not question the construct itself.

Taylor, S. J., & Bogdan, R. (1989). On accepting relationships between people with mental retardation and nondisabled people: Towards an understanding of acceptance. Disability, Handicap & Society, 4, 21-36.

The authors discuss a "sociology of acceptance" as a theoretical model for understanding relationships between people without disabilities and people with mental retardation. They state that family, religious commitment, humanitarian sentiments, and feelings of friendship are all sentiments expressed by nondisabled people who have relationships with people with mental retardation.

Taylor, S. J., Bogdan, R., & Lutfiyya, Z. M. (Eds.) (1995). The variety of community experience: Qualitative studies of family and community life. Baltimore: Paul H. Brookes Publishing Co.

The editors present qualitative case studies that focus on people with disabilities

living in communities and assuming roles as full members of society. The studies present the perspectives of the people with disabilities or their families, rather than service providers. This provides the opportunity to understand how people with disabilities make choices, earn a living, form friendships, and maintain family relationships.

Law and Policy

Braddock, D., Hemp, R., Bachelder, L., & Fujiura, G. (1995). The state of the states in developmental disabilities (4th ed.). Washington, DC: American Association on Mental Retardation.

Published by the AAMR, this book provides a financial analysis of mental retardation and developmental disabilities services on a state by state basis. The information is statistical and is presented in the forms of graphs, charts, and tables. Information covers the last 16 years, and includes an analysis of trends in developmental disability services, profiles of resource allocations and service delivery, and technical information. Topics covered include institutional services, closure of institutions, trends in community services, and costs of care.

Lakin, K. C., Braddock, D., & Smith, G. (Eds.) (1994-2000). Trends and milestones. Mental Retardation.

This is a regular one-page feature of the journal, Mental Retardation. "Trends and Milestones" summarizes current national data on issues such as institutional closures, state and national deinstitutionalization trends, and federal and state expenditures for developmental disability services.

Rothman, D. J., & Rothman, S. M. (1984). The Willowbrook wars. New York: Harper & Row.

Documents events that occurred after court ordered reforms of Willowbrook, an institution for people labeled mentally retarded. Rothman and Rothman follow events at Willowbrook from 1975 to 1982 in an attempt to understand social reform and its implications for people being institutionalized.

Taylor, S. J. (1988). Caught in the continuum: A critical analysis of the principle of the least restrictive environment. Journal of The Association for Persons with Severe Handicaps, 13 (1), 41-53.

This article examines the principle "least restrictive environment" and the associated "continuum" concept which have served as frameworks for the design of residential, vocational, and special education services for people with developmental disabilities. The author identifies the conceptual and philosophical flaws underlying these notions and argues for the need to develop new concepts and principles to guide the development of services.

Wehman, P. (Ed.) (1993). The ADA mandate for social change. Baltimore: Paul H. Brookes Publishing Co.

Contains articles that explore the importance of the ADA and its impact for people with disabilities and specifically people labeled mentally retarded. The articles explore such issues as educational reform, family empowerment, employment opportunities, reasonable accommodations, and attitudinal changes.

Parent and Family Issues

Ferguson, P. M., Ferguson, D. L., & Jones, D. (1988). Generations of hope: Parental perspectives on the transitions of their children with severe retardation from school to adult life. Journal of The Association for Persons with Severe Handicaps, 13, 177-187.

This study explores how parents interpret the events and relationships

surrounding the transition of their children with severe cognitive disabilities from school to adult life. The authors show how transitions are complex, socially constructed processes that need to be understood in both their historical and their cultural context.

Foster, S. B. (1987). The politics of caring. Philadelphia: The Falmer Press.

Foster studied 13 admissions to the Weston Center, an institution for people labeled developmentally disabled. She also studied four people whose applications for admission were denied. She offers discussions on institutionalization and deinstitutionalization, the limits and powers of professionals, and private troubles such as family involvement or lack of involvement.

Turnbull, H. R., & Turnbull, A. P. (1985). Parents speak out: Then and now. Columbus, OH: Charles E. Merrill Publishing Co.

The editors offer a compilation of essays that present the perspectives of parents or relatives of people with disabilities. The essays illustrate that having a child with a disability is not invariably a burden to the family. This second edition offers updates from families profiled in the first edition as well as three new essays.

Contemporary Issues

Dybwad, G., & Bersani, H. Jr. (Eds.) (1996). New voices: Self-advocacy by people with disabilities. Cambridge: Brookline Books.

Documents the self-advocacy movement through a collection of papers by both advocates and self-advocates. It examines the status of self-advocates with developmental disabilities and projects the future of the movement as it expands worldwide. Topics include the historical setting, the self-advocate experience, worldwide views, critical views, and future work in the movement.

Exchange of opinion on the risks and benefits of facilitated communication. (1994). Mental Retardation, 32, 299-318.

A series of commentaries on the potential risks and benefits of Facilitated Communication (FC). The first commentary by Levine, Shane, and Wharton is a critical analysis of FC by leading opponents of FC. This is followed by reaction papers by Ferguson and Horner, Goode, Halle, and Hitzing, none of whom are identified with a pro or con position on this technique. Levine, Shane, and Wharton provide a response to the reaction papers at the end. An editorial introduction provides background on this mini-symposium.

Ferguson, D. L. (1994). Is communication really the point?: Some thoughts on communication and membership. Mental Retardation, 32, 7-18.

This article examines communication interventions as one example of professional efforts to ameliorate the effects of severe disability. The author argues that the real point of such efforts is not so much improved communication as membership in society and that attention should shift from changing behavior to insuring that membership is achieved.

Kennedy, M. J. (1994). The disability blanket. Mental Retardation, 32, 74-76.

Written from the perspective of a person with a disability, Kennedy discusses the problems of being an individual in a service system that invades privacy and takes away choices. He argues that the people with disabilities should be allowed to be in control of their own lives, to receive services when and where they want them, and have professionals consult with them rather than answering to professionals.

Mank, D. (1995). The

underachievement of supported employment: A call for reinvestment. Journal of Disability Policy Studies, 5(2), 1-24.

Despite the thousands of individuals benefiting from supported employment, access to these programs is limited and investment in change is lessening. Mank provides recommendations for change such as new alliances with people with disabilities, investing in community and employers, putting greater control into the hands of people with disabilities, and rejecting the segregation of the current system.

Jacobson, J. W., Mulick, J. A., & Schwartz, A. A. (1995). A history of facilitated communication: Science, pseudoscience, and antiscience. American Psychologist, 50, 750-765.

This article is must reading for anyone interested in understanding the controversy surrounding facilitated communication. According to the authors, facilitated communication is an example of postmodernist trends that have challenged the supremacy of psychological and clinical decision-making. The article demonstrates why facilitated communication has aroused such passionate opposition among certain professionals.

Perske, R. (1995). Deadly innocence? Nashville, TN: Abingdon Press.

Perske documents the life of Joe Arridy, a man labeled "feebleminded" who was forced to confess to the rape and murder of a teenage girl. Despite little evidence, Arridy was convicted and executed in 1939. Perske examines the case against Arridy and the possible connections between being labeled "feebleminded" and confessing to crimes. His arguments offer implications for the present day criminal justice system.

Meyer, L. H., Peck, C. A., & Brown, L. H. (Eds.) (1991). Critical issues in the lives of people with severe disabilities. Baltimore: Paul H. Brookes Publishing Co.

This is an edited book sponsored the Association for Persons with Severe Handicaps (TASH). The book includes TASH resolutions on major policy issues confronting people with severe cognitive disabilities as well as literature reviews and essays authored by major TASH leaders. The contributions to the book provide an excellent summary of recent trends and current thinking on community living, supported employment, social relationships, inclusive education, nonaversive behavioral interventions, and advocacy.

O'Brien, J. (1994). Down stairs that are never your own: Supporting people with developmental disabilities in their own homes. Mental Retardation, 32, 1-6.

O'Brien discusses the recent changes in living for people with disabilities from group home residences to homes of their own. Meeting the challenges of supported living requires new relationships among people who provide and receive supports so that people with developmental disabilities can establish a sense and security of place and of personal control over their own homes and over the assistance they require.

Special topic on facilitated communication. (1994). Journal of The Association for Persons for Persons with Severe Handicaps, 19, 149-199.

This is an exchange of opinion between leading proponents, Biklen and Duchan, and opponents, Shane and Green, of facilitated communication. The exchange of opinion is followed by reaction papers commenting on the pro and con positions.

Taylor, S. J., Bogdan, R., & Racino, J. A. (Eds.) (1991). Life in the community: Case studies of organizations supporting people with disabilities. Baltimore: Paul H. Brookes Publishing Co.

The editors provide qualitative case studies of organizations that support people with disabilities in community places. Topics

covered include organizations supporting children with severe developmental disabilities, and organizations supporting adults with developmental disabilities in their own homes.

(Steve Taylor is Professor and Coordinator of the Disability Studies Concentration in Cultural Foundations of Education and Director of the Center on Human Policy at Syracuse University. Perri Harris is a doctoral student in the Disability Studies Concentration. Preparation of this article and annotated bibliography was supported in part by the National Resource Center on Community Integration, which is funded by the National Institute on Disability and Rehabilitation Research. Of course, the authors' opinions are their own.)

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DISABILITY STUDIES

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RADICAL TEACHER

a socialist and feminist journal on the theory and practice of teaching

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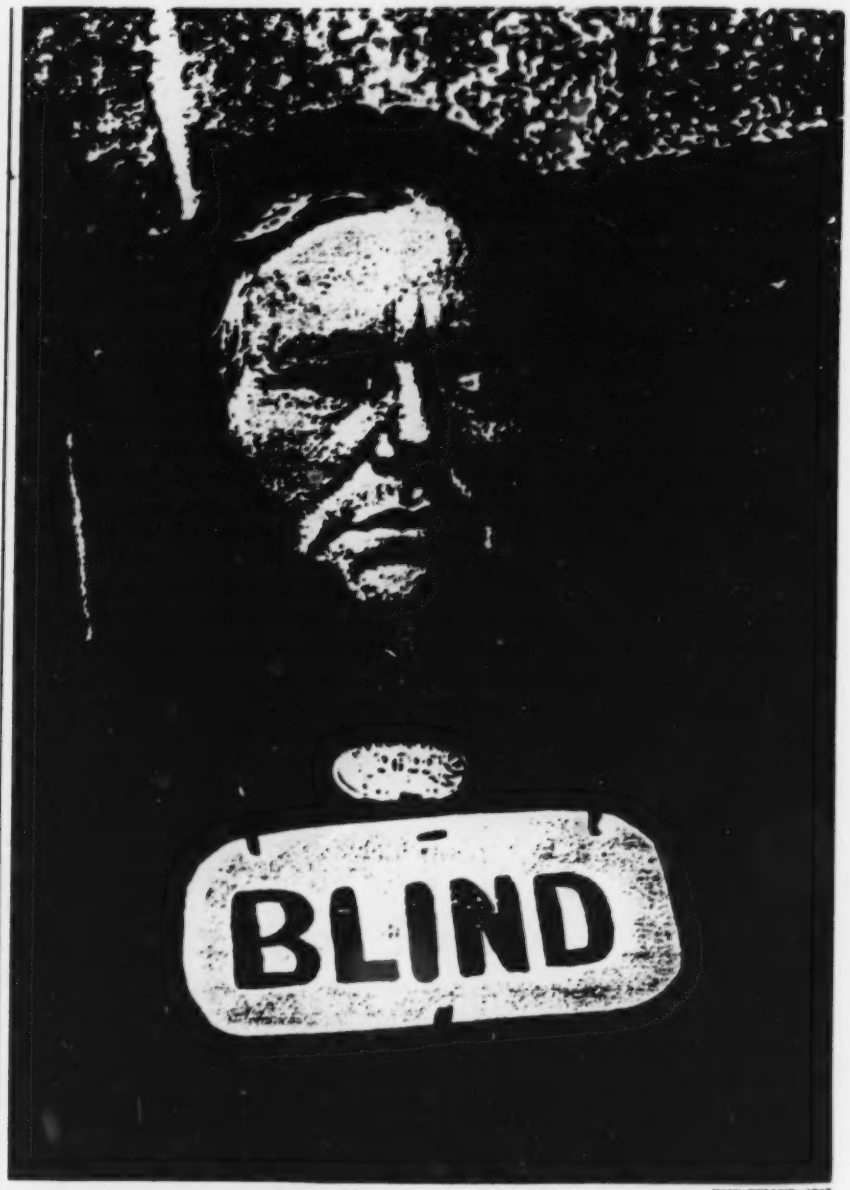
Introduction

BY LENNARD J. DAVIS AND SIMI LINTON

Much of the "new" scholarship, including the work done in feminist studies, cultural studies, queer studies, or racial and ethnic studies, can be seen as a challenge to the notion that biology is destiny. As a result of the elaboration on the social and mutable conditions of people, there are few human practices that are seen as inevitable. There is no social institution, no cultural representation, no policy or interaction that is accepted as an absolutely logical or inevitable outcome of the human condition. And there is no curriculum practice that has not been examined, if only in the most cursory fashion, to understand how it might be transformed to render a more accurate or complete version of the social determinants of experience.

Disability studies, like these other "new" discourses, challenges the assumption that biology, or any physical or psychological variation, destines people to their social status. Disability studies centers the study of disability on its social construction, the processes that have accorded particular meaning to disability and that have determined the treatment and positioning of people with disabilities in society. These are issues central to teaching and to curriculum, yet rarely examined. Therefore, this issue of *Radical Teacher* is devoted to the field of disability studies.



PAUL STRAND, 1917

It is appropriate that we devote time and space to this subject. J. Shapiro[1] states that the population of disabled Americans is between thirty-five and forty-three million, depending on the definition of disability and the source. Although largely relegated to the fringes of society, people with disabilities constitute a significant demographic minority and also constitute a social/political minority. In the same way that people from disparate circumstances are drawn together, for example, under the rubric Latina/Latino, people with a vast array of impairments identify as people with disabilities. When medical definitions of disability are dominant it is logical to group people according to their condition. When disability is redefined as a social/political category, the group is bound by common social and political experience. Framed in this way, disability is no longer understood solely as a personal condition, but a source of identity and a mechanism to organize one's own experience, as well as a starting point for social ac-

tivism. The powerful legislation passed over the last twenty years to accord basic civil rights and equal opportunity is the direct result of such activism.

These political changes and the shift to a socio-political model of disability culminated in the passage in 1990 of the Americans with Disabilities Act (ADA), a major piece of civil rights legislation designed to protect people against discrimination based on disability. The definition of disability under the ADA is consistent with the socio-political model employed in disability studies. A person is considered to have a disability if he/she:

- has a physical or mental impairment that substantially limits one or more of his/her major life activities;
- has a record of such an impairment; or
- is regarded as having such an impairment.

The ADA recognizes that social forces, such as myths and fears regarding disability, function to substantially limit opportunity. The last two parts of this definition acknowledge that even in the absence of an impairment, people can be discriminated against. For instance, this may occur because someone has a facial disfigurement or has, or is suspected of having, HIV or mental illness.

Disability studies, like these other "new" discourses, challenges the assumption that biology, or any physical or psychological variation, destines people to their social status.

Yet, the discrimination and oppression that disabled people experience are largely hidden from the eyes of most people. The dominant ableist discourse has shaped the way disability is described, obscuring the political reasons for the group's marginality. The left, perhaps most egregiously because of its commitment to equality and diversity, has not actively engaged with disability issues. Political solidarity is needed now when many rights and freedoms are in jeopardy. Further, people with disabilities are particularly vulnerable to the impending cutbacks in social services, medicaid, medicare, and public education. The vulnerability is due as much to discrimination in housing, education, and employment as to the specific needs of disabled people. Disability is disproportionately represented among people living in poverty, women, elderly people, inner city residents, and people in developing countries. Attention needs to be paid to the factors that contribute to this pattern as well as to the marginality of disability resulting from the marginal nature of the groups most affected.

If disability were more readily understood as a political issue, it would be taught alongside the more accepted categories of race, class, and gender by teachers committed to diverse perspectives. Although some recent elementary school curricula have included disability as an aspect of diversity, disability is often presented in the framework of helping people get along with each other, to increase what is called "tolerance" for others. The secondary curriculum does little beyond present human interest stories and tales of courage and fortitude, described in the disability community as tales of "overcoming." A more radicalizing curriculum is needed.

The higher education curriculum has not done any better. Traditionally, the study of disability has been isolated in the specialized applied fields (e.g., special education, rehabilitation psychology, health care) and information there, usually available only to majors in those fields, is concerned with remediation, treatment, care, and cure. Further, that curriculum has been developed from the perspectives of the clinician, teacher, or practitioner and perpetually casts people with disabilities in the role of patient, student, or client. Disability studies offers an alternative framework, one focused on social and political variables that shape these roles and their interactions.

The dilemma for disability studies scholars has not been in documenting the social construction of disability; it has been in negotiating obstacles encountered when attempting to relocate and reframe the study of disability in the academic curriculum. Efforts to locate the study of disability in the liberal arts are thwarted, in part, because the academy is entrenched in a particular vision of disability, one so focused on its biological or medical properties that the study of cultural representations and social practices is rarely considered. It may seem like business as usual that the perspectives of people with disabilities are not present in the traditional curriculum, but what is more confounding is that these perspectives have been marginalized in the discourse on diversity and pluralism.

For this reason, and many others, this issue of *Radical Teacher* examines the experiences of some teachers who have developed courses that regard disability in a new light. Linton, Mello, and O'Neill describe the overall parameters of disability studies and attempt to show how this field can apply across a broad range of standard courses now taught. Collins, Schneider, and Kroeger describe their experiences teaching a course at the University of Minnesota to local K–12 school teachers about images of people with disabilities in literature, film, and the media. Bauman and Drake tell how they included a section on deafness in a course on multicultural literature, and Thomson relates her experience of teaching about disability in a women's literature course at a historically black university. An extensive bibliography contains relevant works on disability studies, and Bauman presents a review of books on deafness that can be used as texts in literature courses. While these articles do not begin to address all the issues in the field, the editors hope that they open a window onto a subject which is slowly entering the broader public consciousness and even more slowly entering the academy.[2]

The dominant ableist discourse has shaped the way disability is described, obscuring the political reasons for the group's marginality.

NOTES

[1] J. Shapiro, *No Pity: People with Disabilities Forging a New Civil Rights Movement* (New York: Times Books/Random House, 1993).

[2] For a list of Disability Resources, see News for Educational Workers in this issue. □

Disability Studies:
Expanding the Parameters of Diversity

BY SIMI LINTON, SUSAN MELLO, AND JOHN O'NEILL

ENTER DISABILITY STUDIES

As with many of the new interdisciplinary fields, creating the category "disability studies" didn't create the scholarship. Instead, the name organizes and circumscribes a knowledge base that explains the social and political nature of the ascribed category, disability. The formal establishment of the field some fifteen years ago provided an organizing structure for research and theory across the disciplines focused on disability as a social phenomenon, a perspective largely ignored or misrepresented in the curriculum. The Society for Disability Studies is the home base for the field and journals, such as *Disability Studies Quarterly* and *Disability and Society* (published in England), the most likely venues for work in this area. These are largely unknown to the academic community.

The group that wrote this article are founders of the Disability Studies Project, a curriculum development project we began at Hunter College to acquaint faculty with the field and to lobby for its inclusion in the diversity initiative that had been proposed at the College a few years ago. A diversity requirement was proposed for undergraduate students but despite concerted effort on the authors' parts and efforts of others at the College, the proposed requirement did not include the category of disability studies as one of the areas of underrepresented scholarship that students could choose from in fulfilling part of their requirement. The people opposing its inclusion were for the most part those who were in favor of the initiative—in other words, people like *Radical Teacher* readers—those committed to exposing students to a more representative version of the world. This article and the bibliography that follows were developed at the Project, and an earlier version of these were distributed to faculty at Hunter with the hope that they would find disability studies a challenge to the accuracy and comprehensiveness of their curricula. We welcome this opportunity to present it in *Radical Teacher* and hope that you can use the material in your work. We also hope that it stimulates readers to evaluate their own formulations of the construct "disability," not to mention "multiculturalism."

Woodcut of a blind beggar, from "Werner Rolewinck, Fasciculus temporum." (Strassburg, Johann Prüss, not before 1490.)

DISABILITY STUDIES: AN OVERVIEW

The social, political, and cultural analyses embodied in disability studies form a prism through which one can gain a broader understanding of society and human experience, and the significance of human variation. As Longmore (1992, personal communication) points out, disability studies deepens the "historical comprehension of a broad range of subjects, for instance the history of values and beliefs regarding human nature, gender, and sexuality; American notions of individualism and equality, and the social and legal definition of what constitutes a minority group."

A disability studies perspective adds a critical dimension to thinking about issues such as autonomy, competence, wholeness, independence/dependence, health, physical appearance, aesthetics, community, and notions of progress and perfection. These issues pervade every aspect of the civic and pedagogic culture. They appear as themes in literature, as variables in social and biological science, as dimensions of historical analysis, and as criteria for social policy and practice. Scholarship in this field addresses such fundamental ideas as who is considered a burden and who is a resource, who is expendable and who is esteemed, who should engage in the activities that might lead to reproduction and who should not, and, if reproduction is not the aim, who can engage in erotic pleasures and who should not. Looking at these issues from a disability studies perspective puts into relief patterns of behaviors and policy that have significant consequences for disabled people.

Within most academic curricula, the meaning accorded to disability is that it is a personal medical condition, rather than a social issue; an individual plight, rather than a political one. This state of affairs is remarkably similar to the traditional representations of women, described by Carol Tavris (1992) in *The Mismeasure of Woman*. Her book describes the way traditional research has often measured women against some idealized male norm and attempts to explain behavioral differences in terms of perceived biological or psychological differences, rather than differences in power and circumstance. Thomson (1990), in discussing the position of people with disabilities in society, reminds us of the power differential between non-disabled and disabled people, reinforced because "the dominant group defines itself as normative" (p. 238).

Disability studies challenges the idea that the social and economic status and assigned roles of people with disabilities are inevitable outcomes of their condition, an idea similar to the argument that women's roles and status are biologically determined. But disability studies goes beyond cataloguing discrimination and arguing for social change. It challenges the adequacy of the content and structure of the current curriculum. As with women's studies, disability studies redresses omitted histories, ideas, or bodies of literature and also analyzes the construction of the category "disability," the impact of that construction on society, and on the content and structure of knowledge—fundamental epistemological issues.

Unfortunately, both the structure and the content of the traditional curriculum are problematic with respect to disability. The current structure of the curriculum not only isolates the topic of disability in applied fields, but further segregates it in specialized applied fields (e.g., special education, rehabilitation medicine, counseling and psychology, physical therapy). The academy's role in supporting these specialized areas of study is to graduate majors to staff the kinds of civic institutions that provide remediation and treatment services to people with disabilities. Although there is a need for intervention and treatment, and a need for curricula to prepare professionals in these fields, this approach does not provide a liberal arts education.

The specialized applied fields conceptualize disability as a problem that resides in the individual requiring remediation, treatment, or intervention to amend or compensate for what is perceived as wrong, missing, or dysfunctional. This way of viewing disability is sometimes referred to as the deficit model or medical model. The liberal arts curriculum either represents people with disabilities as deviant or abnormal or, more often, ignores the topic.

Incorporated into the liberal arts curriculum, disability studies has the potential to organize and critique representations of disability, expose ways that disability has been constructed as label and category, and reveal the consequences of those actions for the lived experience of people with disabilities. We have organized information below into modules that can fit in a range of courses and can serve as an introduction to disability studies. We hope, of course, that you go beyond the "add and stir" method of curriculum transformation and continue to mine the information in this issue for ideas that can have a more transformative effect on your work.

EXAMPLES OF THE SCHOLARSHIP

Disability studies captures and organizes works from seemingly disparate areas. It offers insight into the social arrangements constructed around the configuration of the world into disabled and non-disabled, and examines the ideas and beliefs that maintain that bifurcation. Material available comes primarily from the United States, Britain, and Australia, with some recent additions from Africa and Asia. The field both emanates from and supports the disability rights movement, which advocates for civil rights and self-determination based on a minority group model. The field is a form of cultural studies, but one clearly identified with a political movement.

The following material from the field of disability studies is organized into six modules that can be integrated in a wide range of courses. But these offerings only scratch the surface of the wealth of material available and hint at the possibilities of the field to transform curricula.

I
METAPHOR

Metaphors endure in a culture because they are evocative and persuasive ways of explaining something and organizing the way we think. Their power and utility are dependent on shared beliefs and assumptions. Women and men with disabilities, and disabilities themselves, are used as metaphors in countless texts. In *Illness as Metaphor*, Susan Sontag (1978) attempts to separate the essential from the nonessential aspects of illness and, by inference, disability. Her purpose is to liberate our thinking from the "punitive or sentimental fantasies concocted about illness" (p. 3). Kriegel (1982), in a discussion of Sontag's work, notes that "disease has become so all-embracing a metaphor that its actual physical consequences have been swallowed up by the welter of moralistic judgments it calls forth" (p. 17).

Disability metaphors abound in fiction. Thomson (1990) faults literary criticism

for ignoring the social and political aspects of disability and treating "the representation of disability under the rubric of 'the grotesque'." This " invites treating disability as monstrosity and alien otherness, dehumanizing us, erasing our histories, and appropriating our experiences for aesthetic purposes" (p. 238).

We were struck by an example of this guilt by association in a passage that appears in the front of Elizabeth Kamarck Minnich's excellent book on curriculum transformation, *Transforming Knowledge* (1990). The book presents a framework for understanding the limitations of the traditional curriculum and prescriptions for transformation. Ironically, in an effort to demonstrate the importance of representing women's voices, Minnich chose an opening epigraph that reduces the representation of a man with a disability to a metaphor for inadequacy. The quote is from Anna Julia Cooper's *A Voice From the South*, written over one hundred years ago—in 1892.

> It is not the intelligent woman vs. the ignorant woman nor the white woman vs. the black, the brown, and the red, it is not even the cause of woman vs. man. Nay, 'tis woman's strongest vindication for speaking that the world needs to hear her voice . . . The world has had to limp along with the wobbling gait and the one-sided hesitancy of a man with one eye. Suddenly the bandage is removed from the other eye and the whole body is filled with light. It sees a circle where before it saw a segment. The darkened eye restored, every member rejoices with it.

This is certainly an evocative quote. Yet, the utility of the passage is dependent on the belief that someone with the use of one eye perceives only a segment of the world, is unsteady, is hesitant, and functions in a body filled with darkness. The parallels drawn between silenced women and disabled man, and then between women given a voice and a man who is "cured" appear to be as meaningful today as they were in 1892. The dilemma now for those who advocate curricular transformation is to find ways to give the one-eyed man a realistic voice. If he remains a metaphor, his experience is defined only by implied comparison to unsteadiness, darkness, limited vision, sadness, ineptness, the absence of light and enlightenment, and any number of other substitutions for the lived experience of women and men with disabilities.

Courses in literature, literary criticism, rhetoric, or philosophy can investigate these metaphors and other devices that seem appealing because they effectively evoke feelings or images that many are thought to share. Not only do such figures of speech further objectify and alienate people with disabilities, they perpetuate stereotypes.

II
SOCIAL ARRANGEMENTS: THEIR EARLIEST BEGINNINGS AND CURRENT INTERPRETATIONS

To examine variability in social arrangements of people with disabilities, it is best to start at the beginning. Trinkhaus and Shipman (1993) describe the fossil remains of a Neanderthal male who is believed to have sustained serious injuries which resulted in impaired mobility, partial blindness, and the use of only one arm. He lived for thirty to forty-five years, a long life span. The authors comment that his survival was a result of the "compassion" and "humanity" of the Neanderthals. Stephen Jay Gould (1988) describes an individual from the Upper Paleolithic period whose remains indicate physical disabilities (a form of dwarfism resulting in limited mobility) that would have restricted his participation in the hunting and gathering activities, and the nomadic life of his group. The man was buried in a cave that appeared to be a burial site for people of high status. Gould speculates that his social standing may have afforded him this honor, or that his differences were valued, or that "his deeds or intelligence won respect despite his physical handicaps" (p. 18). The paleontological evidence as well as the contemporary interpretations are valuable reminders of the variation in response to disability.

Scheer and Groce (1988) also review information on prehistoric life and critique the narrow and stereotypical interpretations of the evidence in contemporary literature. They note that in prehistoric societies, people with disabilities existed in greater numbers than current evidence would suggest. They compare interpretations of that data with interpretations of the situation of people with disabilities in contemporary nonindustrialized societies. They refute some commonly held assumptions that "disabled individuals born outside the industrialized world were either killed at birth or died when young" (p. 24). Although these practices did and continue to occur, there is tremendous variation in the practices and in the value systems that determine them. They note how scholars in the United States tend to glorify the modern industrialized nations' treatment of people with disabilities and that tendency shapes interpretations of data. For instance, they quote Birdsell (1972) from a standard textbook on biological anthropology: "Biologically handicapped children are a humanistic concern in our society whereas in simple human populations they died early and were not missed" (p.384). Scheer and Groce argue for analysis of the social construction of disability within a given society, as well as analysis of the reconstruction that takes place in scholarship as meaning is accorded to data collected about that society.

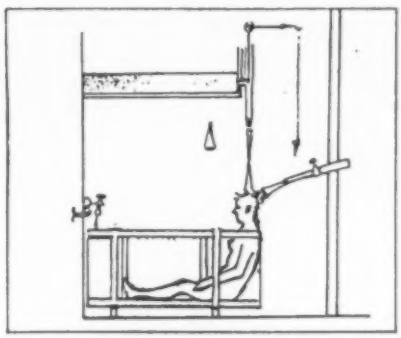
Nichols also comments on the misinterpretations of traditional societies that exist in contemporary scholarship. His study of traditional African attitudes toward disability is in response to the "observable tendency to reduce African ideas about disability to a few hackneyed scenarios whereby disability is seen either as a result of witchcraft . . . or as a form of divine retribution" (p. 26). He notes that modern industrialized societies tend to dismiss African ideas as "barbaric" or "primitive." Instead, he differentiates between African belief systems based on "*pragmatic spirituality* that reflects knowledge and utility, and *blind superstition* which is in bondage to ignorance" (emphasis added by Nichols) (p. 29), in order to demonstrate the human and humane ideas that inform many African approaches to disability. Courses in history, anthropology, ethics, biology, physical anthropology, African studies, paleontology, or cultural studies might examine any one of these topics from an informed disability perspective. These courses could provide useful perspectives on the ways that researchers' ideas can color the collection and interpretation of data and show how disability is subject to misinterpretation.

III
NINETEENTH- AND TWENTIETH-CENTURY BELIEF SYSTEMS

Courses in social history, American or European history, the social foundations of education, or religion might trace

variations in beliefs about disability across a particular time period, such as the nineteenth to mid-twentieth century in the United States and Europe. Longmore (1987) discusses beliefs about disability that were dominant prior to the nineteenth century. It was believed that disability was caused by supernatural agency. Often people with disabilities were thought of as possessed by the devil, punished by god for their sins or their parents' sins, or, alternately, blessed by god and possessed of supernatural powers. The practices that emerged from these beliefs ranged from punishment, isolation, infanticide, or ridicule to overprotection and deification. The latter, although preferable in some ways, offered people with disabilities little control or opportunity.

In the nineteenth century, there was a shift from the belief that disability was caused by supernatural agency to a bio-



Noncooperative patients tied in a saltwater tub and punished with a hosing in nineteenth-century Germany.

logical explanation that viewed treatment, or some form of rehabilitation, as the only logical response to disability (Longmore 1987). This shift marked the birth of an enormous "care" industry and along with it a variety of institutions and asylums.

The field of education developed its own response to the biological explanation of disability. The birth of special education was based on a humane belief in the right of all children to an education and an optimism about people with disabilities not present in supernatural explanations. Even though special education doesn't rely solely on medical diagnoses, the field by definition forefronts the physical, cognitive, and sensory impairments of individuals. The diagnosis and label become the major defining variable of learners, and pedagogical practice is largely determined by these designations (Linton 1994).

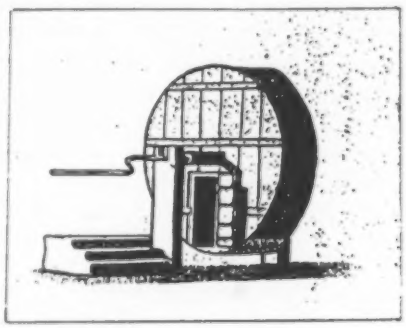
In a variety of courses, this material can be examined as a means to trace the shifts in policies and practices throughout history. Ideas ranging from ancient philosophies to current belief systems can be mined. It would be particularly interesting to examine ideologies popular in America in the nineteenth and early twentieth century, such as Malthusianism, social Darwinism, the science of eugenics, and laissez-faire approaches to government to understand their influence on the accommodation of people with disabilities in the society. These ideas certainly influenced nineteenth-century practices with respect to disability and the vestiges of these ideas persist today.

IV
SOCIAL CONSTRUCTION

Faculty in various disciplines try to explain social construction to students. The idea that disability is a construct is particularly difficult to understand and therefore it is a useful and challenging test case. Students in one of the author's classes (Linton's Social and Psychological Aspects of Disability) have made some very useful connections among various forms of social construction when we have discussed some of the following examples of variation in different societies' treatments of groups we currently call "disabled."

Two examples are provided here to demonstrate cultural responses to disability that are likely to differ from most students' own experience. Nichols (1993), in a discussion of various African cultures' beliefs about disability, describes the concept of Ebih, which refers to "aberrations which violate the natural order of things" (p. 32). He notes that "in the past among the Igbo and some other groups infanticide sometimes occurred following the birth of twins" because multiple births are associated with animals. Infants believed to have mental retardation as well as twins were "thrown away" in the bush because they were considered to be animal-like. These are practices that were frequently used in the past, but are no longer actively practiced. The point, though, is that by shifting time and location, twins and infants considered retarded, as well as other infants with physical anomalies, become part of one group, considered undesirable and more animal-like than human.

Disability, specifically deafness, was constructed very differently in Martha's Vineyard, Massachusetts from the eighteenth to mid-twentieth centuries. For over two and half centuries, ending in 1952, there was a higher incidence of hereditary deafness than in the rest of the United States. There were approximately 72 people who lived in Martha's Vineyard in those years who were deaf, approximately one in every 155 people born. Although a very small percentage of the population was deaf, the community was largely bilingual. As one of the surviving hearing members of the community recalls, everyone spoke sign language and the hearing citizens also used spoken English. In Groce's (1985) ethnohistory of Martha's Vineyard, *Everyone*



Nineteenth-century "hollow wheel" used in asylums to bring the obstreperous to obedience.

Here Spoke Sign Language, she demonstrates how this community located people with disabilities as insiders, not the "other," by accommodating the customs to insure integration of all people in the community. The people who were deaf participated fully in the economic and social life of the Vineyard. It is likely that they lived more like non-deaf people than deaf people did in any other community in the United States.

These examples show the variability and arbitrariness of the division between disabled and non-disabled people. There is not an absolute and inevitable way of organizing the world. In one case, twins, a group not stigmatized or disenfranchised in most cultures, were systematically eliminated in the same manner as people with significant retardation. In the

(Dis)Abling Images

BY TERRY COLLINS, MARJ SCHNEIDER, AND SUE KROEGER

Since 1993, we have been creating, revising, and teaching "(Dis)Abling Images in Literature, Film, and the Media" at the University of Minnesota-Twin Cities. Offered through the Program in American Studies, the course is part of a summer institute immersion experience on diversity and curriculum transformation. As such, the course attracts local K–12 school teachers and special education teachers. One of few "disability studies" courses on our campus, it likewise attracts disabled undergraduate and graduate students and activists seeking in their coursework some structure for serious study of disability identity and culture.

"(Dis)Abling Images in Literature, Film, and the Media" springs from our shared understanding that American cultures and sub-cultures are not sealed from each other but, to the contrary, form each other interactively. We chose analysis of images from the popular media of film, television, and literature as the course's intellectual center because we locate in those images significant defining power: through literary and electronic media images are defined the terms of "normalcy" and "disability," of center and margin, of power and powerlessness. We focus on these familiar images because the culture is shaped in its ideology of disability through such signs.

That is, the course assumes that movies, television programs, and imaginative literature tell us and our students *who* we are and *how* we are. In their recurring themes, these media serve to sustain endless consumption in the pursuit of bodily perfection. So charted, these media name people with disabilities as *other*—irrevocably flawed, useless, dependent, sexless, evil. From Quasimodo to Jerry's Kids, from Tiny Tim to Freddie Krueger, the images manufacture (the more current "construct" seems too polite, too clean) disability as deviance from perfectibility, and people with disabilities as deviants or victims or ciphers, as

"'Tis dark without, 'tis light within." (c 1855–60)

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recognition of students with disabilities as members of an underrepresented minority group, are not addressed.

A fourth obstacle has been revealed as groups at various institutions have tried to broaden the definition of diversity. For example, attempts to include lesbian and gay studies or disability studies in curriculum transformation efforts have been welcomed by some, and criticized by others. Ironically, some of the critics are those who are the strongest proponents of diversifying the curriculum. However, their conceptualization of diversity does not include disability. What is even more disturbing is that the criticisms previously heard from proponents of the traditional canon are now being used against the inclusion of disability in curriculum transformation efforts. The following have been said to one or another of the authors in meetings or at conferences on diversifying curricula: "scholarship on disability will 'water down' the diversity requirement"; "its purpose is to increase self-esteem, or capitulate to interest group pressure"; "it's not valid or rigorous scholarship"; "it's parochial, and will further atomize the curriculum."

Were these criticisms framed as questions to be engaged with, the academic community would benefit from the discourse. Why, for instance, is scholarship on disability not considered rigorous, and therefore likely to dilute or compromise the curriculum or diversity initiatives? Has the association of the topic of disability with the applied fields weakened its status and its perceived applicability to other areas of inquiry? Is disability studies considered only for the purpose of raising self-esteem because people with disabilities are perceived as needing a boost? Is disability studies any more, or any less, related to political considerations or identity formation than any other area of inquiry? Are concerns about a parochial, narrow, balkanized curriculum based on the view that the study of disability is about "them" and says nothing about social, political, and cultural processes that the whole society engages in?

These questions about disability studies relate to broader questions about curricular reform efforts in general. For instance, how can we redress problems in the structure as well as the content of the curriculum in reform efforts? How do the structure and status of the disciplines privilege certain points of view and bodies of knowledge? How does the structure of the multicultural curriculum privilege certain points of view and bodies of knowledge? How does the structure of the disciplines constrain our explorations of new epistemologies that can enhance understanding of the social and political situation of people with disabilities and other disenfranchised groups?

Engaging these questions can provide a more open forum to discuss how disability studies can be incorporated in curriculum reform efforts. Whatever the reasons, diversity/multicultural initiatives have formed their own shape and texture and render their own authority. Therefore, the knowledge these initiatives privilege and the knowledge they marginalize warrant consideration, particularly from the perspectives of the margins. The perspective of disabled people and the field of disability studies are conspicuously absent from a broad range of endeavors. The decisions that have determined their absence are for the most part invisible, giving the impression that these curriculum projects circumscribe the only logical domain of curriculum reform. One hopes that readers of *Radical Teacher* will be among those opening up discussions on this state of affairs and reconsidering how to construct accurate and comprehensive curricula.

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they or friends have had with medical professionals who, they report, pushed them in covert and overt ways to have testing. The students often conclude that a pregnant woman should have the opportunity to learn more about the disability that a child might have, and about the opportunities and resources available for the family and the child. Women need support when they choose not to have testing or choose to proceed with a pregnancy if disability is a possibility. As Hubbard (1990) states in *The Politics of Women's Biology*:

> a woman must have the right to terminate a pregnancy whatever her reasons, but she must also feel empowered not to terminate it, confident that the society will do what it can to enable her and her child to live fulfilling lives. To the extent that prenatal interventions implement social prejudices against people with disabilities they do not expand our reproductive rights. They constrict them. (pp. 197–98)

Other measures to limit the population of people with disabilities are part of the history of medical practice. Elks (1993) notes the horrible conditions of custodial institutions, including overcrowding, poor sanitation, and meager food rations. Death from tuberculosis and pulmonary and infectious disease accounted for over sixty-five percent of deaths between 1901 and 1925 in those institutions. This history is rarely discussed in the applied fields, which tend to underscore the humane and benevolent accomplishments of the medical fields.

Medical practices share a peculiar border with such social institutions and rituals as freak shows and carnivals. Fiedler (1978) in *Freaks* and Bogdan (1988) in his book *Freak Show: Presenting Human Oddities For Amusement and Profit* describe how people have been put on public display in circuses and other more sedate institutions, such as museums and medical facilities. A man described as the "Elephant Man" and a woman called the "Hottentot Venus" were displayed in medical and scientific settings, as well as in commercial venues. People have worked in these areas out of economic necessity or because they were under the "care" of medical personnel and had little opportunity to pursue other goals. Either as scientific specimens or amusements displayed for profit, people with disabilities were denied basic rights and freedoms.

Courses in women's studies, history of science, sociology/anthropology of medicine, public policy, ethics, genetics, biology, and philosophy can review this history from a disability studies perspective. Students preparing for careers in medicine or other health related fields should engage in critical examination of the history of their practice. Although ideally that analysis should take place both within the liberal arts undergirding of their education as well as in their training, in reality the internal critique of the applied fields is limited. The presence of disability studies in the liberal arts is the only likely way that students would have access to critical inquiry.

VI
THE SCIENCES' CONSTRUCTIONS OF DISABILITY

Disability studies scholarship examines the processes by which individuals are marginalized in the society based on physical, cognitive, psychological, or sensory variations. The sciences contribute to the decisions about what is valued and who or what is expendable. These disciplines have created the tools to designate what is normal and acceptable and they have the tools to challenge the power and authority of those designations. Women's studies scholarship has examined critically the mantle of neutrality in which the sciences wrap themselves, and disability studies has done the same. The paradigms and constructs employed in scientific theory as well as the methods of investigation are fertile regions to be explored. Often ideas can function on a subtle level, within an overall structure that gives the appearance of universality and comprehensiveness.

Scholars such as Evelyn Fox Keller have examined such subtle phenomena in writing about the social construction of science. Although such scholars may not have intended to reveal anything about the construction of disability, they have. For instance in her book, *Reflections on Gender and Science* (1985), Keller discusses geneticist Barbara McClintock's perspective on how to conduct scientific research, which is one that, as she describes, "pays special attention to the exceptional case" and entails a respect for individual difference and complexity. Rather than dismiss as aberrant members of a species that stray from the norm, McClintock believes that difference is "evidence not of lawlessness or disorder, but of a larger system of order, one that cannot be reduced to a single law." McClintock's approach offers a way to think about the bifurcations that exist in the social arena based on characteristics labeled disabilities. The approach can inform the discussion on ethical issues related to eliminating difference. For instance, the pursuit of certain notions of perfection are demonstrated in efforts to "repair" the individual with a disability or eliminate people with impairments from the population through the use of prenatal screening and selective abortion.

These are examples that can be included in a range of courses. Readings can be drawn from the "Disability Studies Project Bibliography," which is included in this issue.

OBSTACLES TO INCORPORATING DISABILITY STUDIES IN THE CURRICULUM

Despite the efforts of a number of people on campuses across the United States and at institutions in Australia and England, disability studies has not received much attention in the academic community. There are various reasons for this situation. Certainly, the extraordinarily low representation of people with disabilities in academic settings is an important impediment. Whether those individuals would serve as reminders or actively remind the community of the incompleteness of the knowledge we impart to students, their absence lessens the chance for change.

A second obstacle to the incorporation of disability studies in the curriculum is the assumption that disability is already well represented and in its rightful place—in the specialized applied fields. However, as we have noted, a disability studies perspective is not present in the liberal arts or even in the specialized fields.

A third obstacle is the unspoken belief that the university's only responsibility in this area is to provide services for students with disabilities. It is not surprising that the university conceives of its obligation primarily in these terms. The current curriculum supports a helping orientation and the university has adopted the logic of the curriculum. Other agendas, such as curricular reform, affirmative action efforts to ensure representation of people with disabilities on the faculty and in the administration, and the

Martha's Vineyard example, the demarcation that usually exists between hearing and deaf people was erased.

V
THE MEDICALIZATION AND PATHOLOGIZING OF DIFFERENCE

The medicalization of disability, the appropriation of the category by the medical profession, has had various consequences for people with disabilities. Medical explanations of disability replaced, to a degree, supernatural explanations that were dominant in Europe and the United States prior to the nineteenth century. The identification of disability as a medical condition has afforded many people with disabilities significant comforts and health. However, along with those benefits there has been a loss of freedom and of rights.

Medical, educational, and social service personnel have wielded enormous power over people with disabilities using the tools of diagnosis, labeling, treatment, and institutionalization. It is often difficult to explain what is wrong with this arrangement. The seemingly benevolent impulses that drive these practices belie the paternalism and control these tools serve. The arrangement privileges the medical definitions of people's lives over the social and political definitions. The solution to the "problem" of disability is seen as residing in the resources and facilities of the medical establishment, rather than in legislative bodies and social institutions. The arrangement buys into the assumption that people with disabilities are more concerned with cures than rights, are more plagued with their condition than with discrimination. It also assumes that all human variations labeled "disabilities" require a medical definition.

Further compounding of the problem occurs when medical labels are used to designate certain characteristics as pathological, or groups as mad or dangerous. Sander Gilman (1985) in *Difference and Pathology: Stereotypes of Sexuality, Race, and Madness* discusses the "conflation of concepts" (p. 71) that occurs when, for instance, women or African-Americans are linked with pathology. The conflation of disability and pathology seems so inevitable that it is hard to disentangle the two. Pathology itself is a huge construct, difficult to strip down to its essential and useful elements. The non-essential elements, the encumbrances, the imposed meanings and inconstant social practices are discussed in Gilman's work and the writing of Thomas Szasz, R.D. Laing, Michel Foucault, Erving Goffman, Margaret Mead, and even Alexander Solzhenitsyn (in *The Gulag Archipelago*). Each analyzes the manner in which pathology has been constructed to serve social ends and the ways that medical and other institutions have gained control over people through labeling and institutionalization. This history is analogous to the way women's autonomy has been constrained "for their own good," and women's efforts to buck authority and demand their rights have been interpreted as medical/psychiatric problems to be controlled.

The higher education curriculum strengthens the control that the rehabilitation/medical industry and the special education system have over disabled people. The curriculum has been designed to prepare service providers and educators. Indeed, the needs of the market support the logic of a curriculum on disability isolated in the applied fields. One of the major struggles that disability studies scholars face is wresting control of the representation of disability from these specialists. Disability studies lies outside these fields and critiques their orientation toward intervention and cure and their reliance on deficit models of disability.

> The social, political, and cultural analyses embodied in disability studies form a prism through which one can gain a broader understanding of society and human experience, and the significance of human variation.

An examination of medical history through the lens of disability studies reveals other ways medicine has had tremendous control over people with disabilities. For instance, in addition to attempts to minimize suffering and maximize functioning, some members of the scientific community have attempted to make the human race more "perfect" by eliminating people with undesirable characteristics from the population. The belief that disability weakens the genetic make-up of the population has fostered overt and covert eugenics practices, including various means of controlling reproductive rights or socially sanctioned practices to eliminate undesirables from the population. The eugenic movement that informed Nazi Germany's practice of genocide of people with disabilities has been reported in Lifton's (1986) *The Nazi Doctors: Medical Killing and the Psychology of Genocide* and in Gallagher's (1989) *By Trust Betrayed: Patients, Physicians and the License to Kill in the Third Reich*. Other writers have compared these practices to more seemingly enlightened practices in England and the United States. Hubbard (1990)—in a chapter titled "Who should inhabit the world?"—compares British and American practices and ideas during a similar period, such as the practice of forced sterilization of those considered unfit for society. Elks (1993) traces the historical acceptance of euthenic practices that, if implemented, would sanction the extermination of people with mental retardation. The use of the "lethal chamber" option was supported by leaders in the field of mental retardation in the United States before it was applied in Nazi Germany. Wolfensberger (1981) discusses the implications of the Nazi policy of extermination and euthanasia for current thinking in the United States about prenatal screening to determine the status of the fetus and the growing acceptance of the practice of selective abortion when disability is predicted. There are obvious differences between Nazi practices and current practices in the United States. The similarities, however, are less obvious and certainly less discussed. Authors who have located disability more centrally in the discourse point out the dangers of accepting a eugenics approach to the use of prenatal diagnosis as a means of controlling the variation of characteristics within the population.

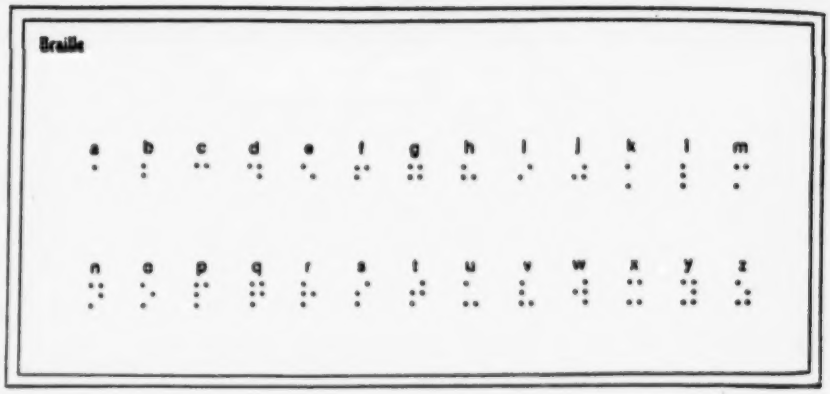
When using these examples in class, it is important to note that raising concerns about the ways pre-natal screening and selective abortion are used and promoted is not to support an anti-choice position. When one of the authors, Simi Linton, discusses this topic with graduate students in counseling we focus on the climate in which decisions are made about pre-natal screening and abortion, not on the right of a woman to make an informed choice—whatever the outcome. Students often comment on experiences

damned, pitiable, absent, or invisible. Learned powerfully and primarily negatively, media images of disability shape the cultural center as the site inhabited by "able" people (by actors and lovers, by doers and agents) precisely because it is a site where people with disabilities (imaged as pitiable or as fearfully or irrevocably flawed, as useless, dependent, sexless, or evil) are missing or are known only safely and trivially.

The debate over canon formation has made clear the power of control over the terms of popular discourse. In querying the terms of representation of disability in the course, we sought to bring to critical consciousness with our students the culture formations through which their prior schooling and established curricula had structured "disability." Furthermore, we sought to provide a site where students with disabilities could confront overtly the imaging which had shaped them and America's perception of them. With all, we hoped to come to know the various cultural purposes served by the creation of such disabling images.

The course came about through administrative and faculty efforts to keep diversity programming vital during a period of backlash and resistance.

To signify this break with prior formations of disability and to shift the discourse toward cultural critique, we deliberately offered the course through the American Studies Program rather than through one of College of Education departments. On most campuses, disability studies courses are located in Educational Psychology or Special Education. We wanted to indicate a new location for disability studies both intellectually and structurally. We knew that the course was a first step locally in what has become a national struggle to claim legitimacy for new versions of disability studies, freed from the constraints of special-educational practice and medical intervention models with which the study of disability has been marked previously. In so doing, we made clear to potential students that this was not another teacher "methods" course



and asserted that disability studies as it emerges will be built on a strong, broad, interdisciplinary base. And while it might seem trivial at first glance, by locating the course in the liberal arts college rather than in a professional school, we opened the course to unrestricted enrollment for students with disabilities who were not registered in Education.

From the very start, our course design and pedagogy have been collaborative. As a team of teachers, we come from quite different positions. Sue works as Director of the large Disability Services office at the University of Minnesota-Twin Cities. In that office, she addresses accommodation needs and campus climate issues and supervises staff who provide or facilitate classroom and workplace accommodations. Marj is Executive Director of the Womyn's Braille Press, consults with educational institutions and industry about disability, and teaches part time on disability and human relations. Both Sue and Marj have visible disabilities and are active within disability communities. Terry is T.A.B.[1], a faculty member in Writing and Literature who has a history of working with campus disability groups, initially entering the field through pedagogical and administrative work on access and from involvement in culture studies and multicultural education.

The course came about through administrative and faculty efforts to keep diversity programming vital during a period of backlash and resistance. Terry had been asked by the summer institute to develop a disability studies course. He agreed to do so on the condition that the course be developed and taught collaboratively with people from the campus disability community and from the very vital off-campus disability scene. University administrators agreed to the logic of that position and to the need for some extra funding to carry the project forward. In practice, the collaboration is structurally uneven and disparately rewarded. As an administrator, Sue has full time commitments beyond the time she manages to set aside for the course and under university rules cannot be paid for her teaching because she receives a full time administrative salary. Although she has since enrolled in graduate school, Marj came to the course as an "outside expert," as a non-academic activist consultant, paid an hourly consultant rate for her work in the course. Only Terry is in a regular faculty line and only he received standard faculty rewards for this work. We are searching for ways to maintain the collaboration and to make the rewards and institutional authority of all participants more equal.

Media images of disability shape the cultural center as the site inhabited by "able" people (by actors and lovers, by doers and agents).

We organized the course around some straightforward objectives. In articulating them at the very start of the syllabus[2] and in referring to them at intervals in the course, we hoped to focus classroom activities on our shared purposes. Given the focus of the summer institute on diversity curriculum for K–12 and special education teachers, we phrased objectives in terms of school dynamics. The objectives are as follows:

- to examine the dynamics of "imaging" of disability in literature, TV, and film, especially in terms of curriculum
- to introduce redefinitions of disability and disability culture(s)
- to speculate about the roles of educators in promoting and resisting "replications" of socially constructed power relationships, with special emphasis on disability as an object of power relationships
- to come to know and own our roles as educators, especially as regards the way our classrooms resist or replicate stereotypes about and stereotypic actions toward people with disabilities, and ways in which our classrooms might promote informed, accurate, and respectful ideas and practices

In addition, to make apparent the shift in power relationships addressed in the course, all materials were prepared in multiple formats *as the default*. As much as possible, we sought to subvert the authority of received assumptions about "normal" media. Readings, syllabi, papers and presentations prepared by students were *all* made available in whatever medium was preferred by any individual member of the class or instructional team. In practice, this meant that most members of the course preferred paper print copies and received them, but others preferred and received audiotaped, diskette (Mac or IBM, at their request), or Braille paper copies of all materials *at the time of first use rather than later as a special accommodation*. All readings were ordered on audio tape well in advance of the course.

> Some of the K–12 teachers used habitual language patterns which are offensive to many people with disabilities.

The required readings are listed at the end of this article. While the reading draws heavily on work familiar to most who work in disability studies, for nearly all of the K–12 and special education teachers enrolled, and for many of the students with disabilities, the reading was not at all familiar. This was new territory for them, despite the fact that it seemed fairly elementary to us and to colleagues consulted in preparation of the course. The core readings consisted of surveys of literary, television, and movie images; disability culture theory; some brief history or prior uses of popular images of disability in genocidal ways; and *Basic Skills*—a collection of short fiction by Anne Finger reclaiming disability. We also critically viewed films where disability is imaged in various ways, from stereotyped figures used in high school film/lit curricula (e.g., different versions of *Of Mice and Men*) to reclamation of disability (*My Left Foot*) to disability sex (*Coming Home*) to the futuristic replications of prior discourses (*The Road Warrior*).

Disability studies and materials which support the field are growing. In 1995, our third offering of the course, we added a historical survey of disability as imaged in film (Norden, 1994) and introduced choices of extended prose to include Jean Stewart's *The Body's Memory* and Susanna Kaysen's *Girl, Interrupted*. We also use the award-winning documentary "When Billy Broke His Head and Other Tales of Wonder," featured on PBS and released in early 1995, as an opening focal point.

Individual or collaborative projects immersed students in other readings or films. Students were encouraged to take the projects in directions that fit their goals for the course. Thus, many teachers created curriculum plans appropriate to the grade levels of their students, while some of the non-teachers used disability culture theory to give new readings to familiar texts. In one instance, non-disabled K–12 teachers collaborated with one of the disabled undergraduates to create a new junior high language arts curriculum segment grounded in Longmore, Gill, and other disability culture theorists.

Our course goals feature personal and cultural transformation. Consistent with that, our pedagogy has been grounded in collaborative learning and focussed discussion in which readings are synthesized and cultural assumptions are examined and challenged. Because we positioned ourselves as a collaborative teaching group with multiple perspectives on the course topic, cooperative learning and exchange were the natural pedagogical choices.

In general, student reaction to the course has been nearly completely positive. Quite frankly, that hasn't surprised us. We know it's a good course, sound in its intellectual formation and purposeful in its structure. What *has* been rather remarkable, however, has been a pattern of conflict and discomfort brought on by empowerment of, by the centering of the experience of, students with disabilities in the course.

Three sorts of proximate issues seem to have caused such conflict. The first should not have surprised us, but did. Some of the K–12 teachers used habitual language patterns which are offensive to many people with disabilities. In the early days of the course, as readings addressed questions of vocabulary and power, exchanges about language such as "wheelchair-bound" or "victim of polio" were neutral. As time passed and offensive habitual language re-entered the conversation, tempers flared in reaction to inadvertent use of such terms. While this diminished with time, it has persisted in ways which puzzle us.

The second has had to do with a more fundamental social disorientation brought on by the course content and structure. Exuberant at finding intellectual ground for liberation from disabling images, being in class for the first time with a critical mass of other students with disabilities, and locating an intellectual community which confirms much of their lived experience, students with disabilities have found a forceful voice in the course. Many of the teacher-students, having been trained in educational praxis grounded in "care-for" and "speak-for" assumptions about people with disabilities, became somewhat defensive in the presence of this newly authenticated voice. In comments on the course evaluation forms, this was addressed anonymously as dissatisfaction with "confrontational" exchanges between disabled

> The course reading, viewing, and discussion overtly dismiss the "medical" and "deficit" models of disability.

and non-disabled classmates. From our collective view, this seems like the inevitably uncomfortable first steps in a healthy realignment of authority, the disorientation that must follow a sought-after relocation of the center.

The third issue seems more intellectually and culturally foundational, and therefore less subject to "adjustment." The course reading, viewing, and discussion overtly dismiss the "medical" and "deficit" models of disability. Moreover, a great deal of classroom energy goes into interrogating the social construction of disability, the resulting media images, and the interplay between the two. Collaterally, readings in disability culture provide an alternative to the entrenched views. The prior education of the K-12 teachers and special educators enrolled in the course, and the curricula in which they have invested themselves professionally, are typically grounded in deficit models of disability and are criticized by social constructivist criticism. Well-intentioned, generous people thus find themselves and their professional identities questioned in this process. An example illustrates this recurring dynamic. One of the students, a middle school language arts teacher, found himself near tears in a class discussion. During the previous year, he had spent a great deal of time working with a young woman who has cerebral palsy who had been mainstreamed into his class. He had coached her in writing an essay in the "C.P. victim-overcoming" or "super-crip-among-the-normals" genre, an essay which had won a national award and brought much recognition to the student. He had taken a great deal of pride in this student's accomplishment. After reading Carol Gill and Mary Johnson (see reading list below), he was profoundly, thoughtfully disturbed. Through the lens of Gill and Johnson, he had come to see his unpaid overtime work and the student's success as being grounded in confirmation of her victim status, in the "bargain" that allowed her success precisely in proportion to her willingness to conform publicly and reassuringly to the dominant image of the "cripple-with-guts." He feared he had done her a grave disservice, in that her greatest success in school had been tied so publicly and so positively to her autobiographized victimhood. Those members of the class who were not disabled tended to reassure him that he had done the right thing in helping to "raise her self-esteem." The students with disabilities, however, tended gently, firmly to confirm his self-critique. The difference in world-views, in disability-epistemology was palpable. And, at least in the space of our course, it was irreconcilable.

> We sought to subvert the authority of received assumptions about "normal" media.

> American cultures and sub-cultures are not sealed from each other.

In sum, we're quite satisfied with the course, at least as a first effort. Working with it has taught us a lot about what to expect as we build disability studies on a multidisciplinary foundation and, in so doing, challenge deeply ingrained intellectual, social, and personal authority structures. We're anxious for this discussion to grow.

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NOTES

[1] "T.A.B." is disability-speak meaning "temporarily able-bodied," a deliberately wry definition of those without disabilities as a function of their non-disability, inverting the accepted use of disability-referents in ascribing status.

[2] The complete syllabus, as revised, is available from Terry Collins, General College, University of Minnesota, 128 Pleasant Street Southeast, Minneapolis, MN 55455; e-mail <tcollins@maroon.tc.umn.edu>. Specify preferred format: print, text file, or Braille. □

Integrating Disability Studies into the Existing Curriculum:

The Example of 'Women and Literature' at Howard University

BY ROSEMARIE GARLAND THOMSON

As a white woman with a quite visible physical disability who is a professor at a historically black university, I envision my role to be introducing complexities into my students' tendency to see race as the primary, if not exclusive, focus of individual and group identity. The centrality of racial history, issues, identity, and community to many of the humanities and social science courses at Howard, as well as the predominant black presence, foster a strong sense of black solidarity among our students. Yet, at the same time, Howard's almost exclusively black student and majority black faculty population also afford the kind of safe atmosphere where distinctions among the black community can be examined without the kind of recourse to minimizing differences in order to establish black solidarity that sometimes prevails at predominantly white institutions. My job at Howard is to invite students to consider how gender, class, and disability bisect racial groupings and to interrogate the very process of social categorization according to physiological or psychological characteristics. While many of my colleagues balance race with gender and class analyses, introducing disability as a category of social analysis is rare. Disability studies is simply not a part of the general educational currency at Howard or at most other institutions. The salience of race as an analytical category at my university seems to me to both obscure and invite an examination of disability as a parallel yet distinct social identity based in corporeal or mental differences. The hyper-awareness of racial considerations often overshadows or minimizes other forms of what I call socially constructed "corporeal otherness" even while it serves as a model for examining those same forms of cultural marginalization. What I intend to discuss here is how I attempt to introduce disability studies—disability consciousness, if you will—in the context of a sustained focus on racial difference and to a lesser extent on gender distinctions.

In the broadest sense, my aim in teaching disability studies is to complicate the received "we" and "they" conception that implies both a victim/perpetrator and a normal/abnormal relationship between the disabled and the nondisabled. To do so, I probe the categories of "disabled" and "nondisabled," questioning their interpretation as mutually exclusive groups who are sorted according to bodily or mental traits. I emphasize the social aspect of disability, its relativity to a standard that is culturally determined, rather than its physical aspect, precisely because our traditional account of disability casts it as a problem located in bodies rather than a problem located in the interaction between bodies and the environment in which they are situated. In short, this pedagogical goal requires removing disability from its traditional medical model interpretation and placing it into a minority model understanding. It means not describing disability in the language of inherent physical inferiority or medical rehabilitation but instead adopting the politicized language of minority discourse, civil rights, and equal opportunity so as to invoke such historical precedents as the Black Civil Rights Movement and the Women's Movement. In other words, by focusing

on the social construction of disability, by framing disability as a cultural reading of the body that has political and social consequences, and by invoking a politics of positive identity, I hope to facilitate understanding and identification across identity groups rather than guilt and resentment. Such an approach is intended to relativize and politicize both the categories of "disabled" and "able-bodied" while casting a critical eye on the cultural processes that produce such distinctions.

Yet, the kind of curricular refashioning that enables me to teach courses in disability studies is not easily accomplished. It is often not feasible or timely to convince institutions to offer new courses whose titles include the term "disability" because it is difficult to classify them. Administrations wish to know

where they fit in the traditional scheme of the disciplines and categories: does disability belong to the humanities, to sociology, to special education, to health or science? More problematic yet, how broad an appeal might such courses have? Disability sometimes seems at first glance like a tangential or narrow field of inquiry, one that would attract only a special population. Although I would argue that disability studies should be a humanities course which, most appropriately, satisfies a diversity requirement, it can be arduous to reframe institutionally what might have been previously perceived as a health course so that it can be understood as minority studies or cultural studies. To diffuse this logic and its accompanying resistance, I propose that we teach disability studies as an integrated part of all the courses we design, just as many of us have begun to consider race, gender, and class issues as fundamental aspects of all disciplines and subjects of inquiry. Indeed, as the disciplines of women's studies and ethnic studies have learned, such categories sometimes foster the assumption that these are the only arenas where racial or gender concerns are appropriately addressed. One of the goals of disability studies should be, then, to knit disability as a category of analysis into all of the courses in which we examine the workings of culture, especially courses that address issues of representation, identity, subjectivity, or the political implications of ideology.

In such a spirit, I integrate disability issues into all the courses I teach as an English professor. By way of example, I will discuss here how I infuse disability studies into a particular undergraduate humanities course called "Women in Literature" that I teach regularly at Howard. I intend to show here, first, examples of material from various disciplines that are not explicitly labeled "disability studies" but which can nevertheless be marshaled to elucidate the way that disability, along with other stigmatized identities, operates in Western culture. Second, I will suggest how literary and cultural analysis might be enlisted to reveal the ways that social relations produce the cultural distinctions of disability, race, gender, as well as class. Third, I will reflect on student responses to the material and the approach.

In all my teaching, rather than focusing exclusively on disability as the sole form of social otherness under consideration, we simultaneously investigate the bodily based social identities of race, ethnicity, gender, and sexual orientation as parallel but distinctive social categories whose function is, among other things, both to differentiate and in some cases to stigmatize individuals on the basis of corporeal differences. By intertwining analyses of a range of identities culturally constructed from bodily traits and behaviors, I encourage students to draw comparisons among them as well as mobilize their own varied experiences of differing types of social marginalization or oppression. Thus, my aim is not to privilege disability identity, but rather to probe the sociopolitical and psychological aspects involved in a matrix of often overlapping forms of social identity which rest on a premise of irreducible corporeal difference.

Even though the course I am assigned to teach at Howard is entitled "Women in Literature," I subtitle it "Human Variation and the Politics of Appearance" with the intention of linking political subordination to the cultural valuing and devaluing of bodies on the basis of their appearance. Centering our inquiry on appearance enables us to discuss not only the system of standards upon which social discrimination draws, but to consider how appearance norms contribute not only to racism but to other forms of social oppression as well. In order to scrutinize simultaneously race, gender, class, and disability, the course undertakes as its primary subject a critical examination of feminine beauty. Since the politics of appearance along with its value system, "beauty," encompass multiple forms of social marginalization, all students can identify with the issues in one way or another. In this way, ableism becomes one variation of a general form of social discrimination rather than an issue that the nondisabled students might think has nothing to do with them.

> Our traditional account of disability casts it as a problem located in bodies rather than a problem located in the interaction between bodies and the environment in which they are situated.

By focusing on beauty as an oppressive cultural ideology perpetuated and enforced by a wide range of institutions and received traditions, we are able at the outset to diffuse any simple split between those who could slip into the normative position in regard to our topic and those who are outside of it. There is no "we" and "they" when it comes to issues of appearance and beauty. It is quickly apparent that feminine beauty is a personal issue for all the students, even the men. Because the course fulfills a university humanities requirement, it draws from a range of ages and the students who enroll represent a wide variety of academic interests and experiences. The majority of students are women, some of whom are sympathetic to and familiar with feminism, some of whom are resistant to assertions of any cultural or historical gender differences, and most of whom are curious about investigating an academic subject that seems so close to lived experience. Men usually comprise ten to fifteen percent of the class. Some of the men are feminists themselves or quite interested in women's issues, while often a handful of the men seem vociferously hostile to the course's persistent focus on the female position. Most students are from middle-class or black elite backgrounds, while some are from the inner-city and are working class or from the working poor. Although virtually all the students are black, they represent a rich diversity of cultural backgrounds—African-American, African, Caribbean, Southern rural, Northern urban, Western U.S., mixed race and nationality—as well as a wide range of notions of what it means to be black. The only confident generalization I can make about black students is that they are black, a social identity which signifies diversely for them.

All the students seem quite eager to discuss and examine beauty standards, body-image issues, women's changing social position, questions of identity and community, and especially relations between men and women (a point I will return to later). Indeed, the course's greatest challenge is managing coherent, focused discussions which draw on per-

sonal stories yet retain an analytical edge. I nevertheless explicitly introduce the feminist assertion that the personal is political so as to encourage sharing personal observations and experiences both in class as well as in the daily reading response journals students are required to keep. What critically and personally scrutinizing beauty eventually allows us to explore is the ways in which cultures saturate bodies with meanings, an essential concept for understanding the disabled category. Along with illuminating how bodies are interpreted within societies, interrogating beauty also encourages students to flush out the value systems and the power dynamics that underpin those interpretations.

At the beginning of the course almost all students rather uncritically assume that beauty is a somewhat fixed property of the female body. Although many students recognize the historical and cultural relativity of appearance standards, they tend to see beauty as an absolute physical quality free from political implications or relations of power. Many students are willing to challenge impossible beauty norms, but few have taken their critiques beyond the arena of personal adequacy or inadequacy. Beauty, they often feel, is something corporeal that one has or does not have—just like a disability. But whereas having a disability seems a disadvantage, having beauty seems an advantage. Few students have considered the disadvantages of beauty. Thus, we further probe the operation of beauty and disability to see the parallels and to uncover the social relations that govern enforcement of bodily norms. What I try to develop is a global critique of appearance norms which at once transcends and draws from students' individual relationships with their bodies and their personal negotiations with beauty demands.

One successful way to do this, I have found, is to shift our attention to beauty's mutually constituting opposite, "ugly," which under scrutiny yields up the recognition that while beauty may not initially seem oppressive, the attribution of its flip side, ugliness, is indeed disempowering—a point I will return to later. Introducing ugliness makes it easier to denaturalize beauty, to show that it is a series of practices and positions that one takes in order to avoid the stigmatization of ugliness. I accomplish this by introducing and juxtaposing two historical figures to the class: one woman who epitomized beauty, Marilyn Monroe, and another woman who epitomized beauty's opposite—not just ugliness, but freakdom. She is Saartje Bartmann, the nineteenth-century African woman known as "The Hottentot Venus," whose body, which was normal in her own culture, differed so much from the European standard that she was recruited into English and French freak shows. By recognizing how constructed Marilyn's beauty was—the hair dye and makeup, the photo techniques, the cosmetic surgery, the name change—and how vulnerable it made her to its transience as well as its exploitation, the students see that beauty is not only a set of practices but that its empowerment is quite limited if not actually detrimental, as Marilyn's biography illustrates so well. What Marilyn and Saartje have in common is that their bodies were displayed for profit before audiences in ways that were not necessarily beneficial to them but that were dictated by the culture's need to articulate formally its standards for the female form.

Hottentot Venus, 1817.

While the students' response to Saartje Bartmann's display as an exoticized, sexualized freak is uniform disgust and outrage, their responses to Marilyn Monroe are usually more varied and complex. Juxtaposing the exploitative display of a white woman and a black woman invites, of course, a consideration of race and its accompanying power dynamics. The students who reveal great hostility toward Marilyn as the figure of perfect white beauty that has been held up to them as forever unattainable are generally softened and their judgment is legitimated by Gloria Steinem's analysis of the star's miserable life. Other students clearly admiringly identify with Marilyn, expressing sympathy that her life was not the fairy tale that they imagined beauty would confer. Regardless of whether they adore or despise her, students generally find shocking the pathology and liability of Marilyn's beauty. For the most part, they are unaware of the ways that beauty is mediated by cultural presentation: they assume that what they see is the natural, unreconstructed woman and that beauty delivers fulfillment. Most students are also astonished that white women try to reconfigure their bodies because they depart from beauty norms. They are very aware of the disparity between female bodies of African heritage and the stylized contemporary white beauty standard, but many do not realize that European female bodies usually cannot conform to the impossible ideal either. For example, students frequently express interest and surprise when I reveal my own conviction about the inadequacies of my hair, which is straight and limp. This sometimes creates a complex dynamic in which students identify across race with white women on the basis of shared gender experience even as they recognize white women's relative

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privilege within beauty culture's hierarchy of bodies. What they witness is an affirmation of what they already know but which cultural pressures mute: that a satisfying life is not so simply linked to looking right. This, of course, lays the groundwork for examining the body's social context and suggesting that the disabled body does not necessarily produce misery.

In order to denaturalize and politicize beauty culture, at the outset of the course we critically view a number of advertisements to catalogue the qualities of beauty which are so hyperbolically and relentlessly choreographed in the pages of women's magazines. With a little guidance, students adeptly and zealously read the images, compiling a stunningly uniform and narrow profile of acceptable body traits for women which include—among others—hairlessness, odorlessness, a prepubescent slimness and youth, softness, whiteness, thick wavy hair, as well as psychological characteristics such as passivity and self-consciousness. While the students are keenly aware of the racist implications in the ads' celebration of European physical features and of thinness, they have not usually thought through the role of women's bodies as spectacles in a consumer society that accords males the role of spectator and actor—a relationship that is writ large, if subtly, in advertising. Analyzing the images and reading theoretical critiques—such as John Berger's *Ways of Seeing*, an exploration of the social relation between the male spectator and the female spectacle in European oil painting—reveals for students a dynamic, in this case gendered and racialized, in which one role is to look, judge, and act while the other role is to be gazed upon, measured, and passive. They begin to understand here that the usually disembodied, usually male figure who has the power to define and to evaluate is seldom pictured in these ads, but that the woman presenting herself before the gaze is displayed for his approval and explication. Such critiques provide the students with explanatory vocabularies which they tend to wield in their journals and essays as they discuss their lives. Often they write authoritatively of spectators and spectacles, of gender and racial systems, and of social constructions.

While the class is certainly a feminist analysis of how beauty operates as sexism, it at the same time illustrates the more general process of how the body is the arena where asymmetrical power relations are acted out. This sets us up for discussing how the categories of normal and abnormal so fundamental to disability oppression are products of a social relationship in which one kind of person has the power to judge and to assume normativeness, while another must submit to judgment. The overwhelmingly female class is thus able to make a leap of identification between themselves as women, particularly black women, and people who have disabilities: they come to understand that the process of objectification that is a part of the ideology of feminine beauty is related to the process of objectification that is part of being considered disabled. Just such a dynamic between the defining subject and the defined object produces the traditional interpretation of physical disability as abnormality or inferiority. Examining this relationship allows us to uncover the power relations involved in the gaze not only in terms of gender and race, but also to relate that concept to "the stare" that is a specific form of social oppression for people with disabilities. The evaluating gaze of the male upon the female can be seen as parallel to the evaluating gaze of the "ablebodied" upon the disabled. One of the students' favorite readings, Alice Walker's autobiographical essay "Beauty: When the Other Dancer is the Self," specifically links disability to the politics of appearance as well as to the matrix of race, class, and gender. This essay interrelates Walker's becoming blind with her loss of femininity and worth and then chronicles how she regained a valued self image. Like the Marilyn Monroe story, this particularized narrative is popular with students because it manifests in an individual life the points that the cultural analyses explicate.

The course also highlights several cultural sites where ambiguity exists between beauty and disability to suggest that the coercive valuing of certain body types over others is what lies at the heart of both disability and beauty oppression. The first of these intersections is the nexus where prescriptions for beauty result in bodily transformations that amount to "disabilities." Discussing such historically and culturally varied practices as corseting, foot binding, clitorectomies, anorexia, and cosmetic surgery reveals to us the cultural relativity of the concept of disability, for such practices are understood in one context as the achievement of beauty or social acceptability and in another context as precisely the kind of bodily transformation that is taken to be a "disability." We particularly focus on cosmetic surgery because it is the practice for normalizing the (usually female) body that seems the least exotic, distanced, or pathological to modern American sensibilities. Indeed, many of the students accept the confessional mode I invite with the reading response journals to reveal anoretic or bulemic tendencies or admit to having considered cosmetic surgery to "improve" their looks or to "correct" what beauty has told them are their deficiencies. Because studies indicate that black women are generally more comfortable with their bodies than white women and generally suffer less frequently from eating disorders, I am surprised that many of my students disclose how inadequate they—often secretly—imagine their bodies to be, how tormented they

are by these convictions, and how willing they would be to alter painfully their bodies to fit the standards. My suspicion is that the studies are measuring class differences more than race differences and that my students are responding to middle-class pressures to conform to beauty norms that underclass women, who are perhaps more alienated from mainstream requisites, might be spared.

Through framing cosmetic surgery as part of the beauty industry and ideology, students can recognize that the surgical normalization of the female body to meet cultural standards of beauty is parallel to the coercive "corrective" procedures that disabled people are often subjected to in order to reform their bodies to meet norms that they defy. Some of the images and discourse we examine are articles and ads on cosmetic surgery that are featured in women's magazines. Critically studying this marketing language enables students to understand how uniform the appearance standard is and how constructed it is even as it masquerades as natural and effortless. Perhaps most interesting is that with both disability and beauty the naturally occurring body is mutilated in order to conform to a standard that is presented to us as "regular" or "normal." Just as rhinoplasty and liposuction sculpt the "ugly" nose or the "fat" hips to the standard contours beauty dictates, surgeons "reconstruct" the disabled body and fit it with myriad prosthetics—often only to police life's physical variations, ones that are apparently so intolerable within contemporary American culture. It is this tyrannical concept of "normal," serving as it does capitalism, white supremacy, and patriarchy, that I want the students to come to question.

Mounting such a comprehensive cultural critique creates some pedagogical dilemmas I am not sure I successfully negotiate. By attacking beauty standards, even if I let the material speak for me, I risk implying that the students are complicit in their own oppression. What floats palpably in the classroom—coming from many sources—is the accusation of false consciousness, the suggestion that the students themselves are being castigated for their participation in beauty practices. More problematic yet is the logic inherent in the critique that caring about men is consorting with enemy. I try to address this problem directly by discussing the concept that there is no place outside acculturation for anyone to be, that we all want to be attentive to our appearance even as we try to avoid being in thrall to it. We talk much about placing ourselves in relation to beauty norms in ways that we can live with. Nevertheless, indictments erupt in class discussions that I try at once to defuse and to play out. The intense hair debate, provoked predictably by Alice Walker's witty and highly politicized essay about "oppressed hair," always provides a forum which at least exposes this dynamic even if we never resolve it. The discussion about what it means and whether or not a black woman should straighten her hair is highly charged with defensiveness, accusations, and humor, serving as a conduit to examining identity politics, the racism inherent in beauty standards, and the politicization of personal practices. The ever inconclusive hair question perhaps best illustrates the complexity of these issues.

Another dynamic that requires scrutiny is what I call coercive agreement. Most students' response to the concept of disability as a site of oppression is that they have never thought about it before. Many quickly and profoundly make the connections I hope to establish with race and gender, while some seem to unreflectively adopt an overly sympathetic attitude that I suspect may be in deference to me because I have a disability and am the teacher. This coercive agreement is one of the hazards of advocating in the classroom for a group to which you belong. Such a situation is one reason I prefer invoking as many manifestations of corporeally justified oppressive social relations as I can to analyze the larger processes at work.

> The hyper-awareness of racial considerations often overshadows or minimizes other forms of what I call socially constructed "corporeal otherness."

One of the liveliest and most polarized of these instances always occurs around the issue of "fat," which lies in a zone somewhere between ugliness and disability, and is often the conduit through which female students come to personally identify with the social stigmatization that accompanies disabilities. While being overweight can constitute a functional disability, the students are quick to see that the social condemnation attached to being obese is usually far more detrimental than the impairment involved. Furthermore, the students' own struggle with our cultural tyranny of slimness enables them to recognize that bodily aberration is relative to a cultural and historically specific standard that serves particular interests, such as the cosmetic or fashion industries, for example. Again, autobiographical essays—Roberta Galler's about being disabled and Carol Munter's about being obese—are read together so that students can compare the subjective experiences of both women. As I mentioned before, my students seem to respond with greater understanding and interest to the identifitory and personalizing mode of the individual life story presented in the subjective voice than they do to theorizing or historical surveys. While each writer concludes that society rather than their bodies needs to change, Munter's movingly account of the denigration of her body because it is fat presents an idea new to most students, who, of course, have internalized the script of blaming the overweight person rather than the impossible standards the culture of beauty demands. Yet, frequently arguments erupt in class when some students frame fat as unhealthy, undisciplined, and inexcusable excess while others fiercely defend themselves or friends and family as victims. Fat—which I point out legally constitutes a disability—is the subject most often mentioned in the reading response journals. It is remarkable how freely some students assail obese people in ways they would never openly denigrate people with disabilities, on the assumption that obesity can be altered by an act of will. The class never reaches consensus on this point or on the lively argument of whether it is appropriate for black women to straighten their hair. Nevertheless, the juxtaposition of disability and fat oppression emphasizes that often the cultural context surrounding and defining our bodies, not our bodies themselves, creates problems for us—and that this context rather than our bodies requires alteration.

To complement the autobiographical accounts and to move the issue of appearance from the individual body into the larger context of social relations and value systems that support power dynamics, we read as well excerpts from historical critiques of those systems such as Naomi Wolf's *The Beauty Myth*, Gerda Lerner's *The Creation of Patriarchy*, Simone de Beauvoir's *The Second Sex*, Elizabeth Spelman's *Inessential Woman*, and bell hooks's *Black Looks: Race and Representation*. Some students find the accounts of the systematic nature of sexist oppression to be a revelation that frees them from a sense of individual failure for their own insecurities as women, while others resist accounts of patriarchy as having so much historical force and precedence. One of the most persistent sentiments among many students—both male and female—is the myopic and rather defensive conviction that women of this generation are fully liberated from the residue of sexism, that the problems are simply gone. It is interesting that students tend to recognize the enduring presence of racism, while insisting that society no longer limits women. Perhaps this is an important enabling progress narrative that should not be questioned; on the other hand, it risks denial and naivety. One of my most difficult challenges is to facilitate a comprehensive critique of systematic racism, sexism, and ableism while still encouraging empowerment and exploring modes of resistance.

So in order to expose the systematic nature of oppression without suggesting that it inevitably overwhelms individual agency, the first part of the course delineates the complex workings of oppression while the second part explores potential strategies of opposition. Because the course "Women in Literature" is offered as an English as well as a humanities course, literary analysis occupies a central place. To this end, we read two novels which place at the center of their social critiques the institution of feminine beauty as it is inflected with racial, class, and gender considerations. First is Toni Morrison's *The Bluest Eye*, a powerful novel which presents how the inextricable, institutionalized forces of racism, sexism, and classism combine to enact the tragic destruction of a young, black girl, abetted by the often unwitting complicity of the very community that might have saved her. The second is Alice Walker's novel *The Color Purple*, which provides a prescription for combatting the complex matrix of forces which attribute "ugly" to certain female bodies. While Morrison's is a descriptive account of the tragic political and personal consequences precipitated by what I am calling "the ideology of beauty," Walker's account offers students an optimistic paradigm for resistance and transformation. Morrison's novel is a tragedy which demonstrates the complexity and relentlessness of oppression and Walker's novel is a comedy (not a funny story but a painful tale with a happy ending) which details the triumph of a woman over those same crushing forces. Taken together, the two novels constitute the dual aspect of cultural critique: a complex articulation of the problem in its multiple material manifestations and a speculative strategy for resistance.

> Most students' response to the concept of disability as a site of oppression is that they have never thought about it before.

As preparation for reading the assigned novels and autobiographical writings, we thoroughly discuss the issue of representation, stressing the ways that representation shapes the reality that it supposedly reflects. We examine the political and ethical consequences of literary representation by reading Susan Sontag's study *Illness as Metaphor*, which elaborates the metaphorical uses of tuberculosis in the nineteenth-century and cancer in the twentieth century in order to suggest the negative consequences that these modes of cultural representation hold for people who have the diseases. Sontag's classic analysis thus allows us to use the representation of disability as a vehicle to understand the representation of race in Morrison's novel.

The juxtaposition of *The Bluest Eye* and *The Color Purple* form the center of the course. Around each novel are clustered the analytical or historical essays and the shorter biographical readings (all of which are listed at the end of this essay) so that Morrison's and Walker's narratives act as individualized testimonies to the concepts the course is designed to examine. The particularization of the issues that the novels accomplish gives the students a sense of reality and immediacy about the ways that the politics of appearance function in the complexity of lived experience. Moreover, their journals, discussions, and essays suggest that the students are able to identify often in profound ways with the two central characters, Pecola and Celie, on the basis of their being judged as "ugly." What Morrison's novel allows the students to understand is that "ugliness" is not located in any objective physical criteria but instead in the ideological systems of denigration that produce "ugliness" as a condition of racism, sexism, and classism, not as a property of a particular body. Yet the students seem to find most compelling the emotional involvement they establish with the characters, the personalization of social and political issues that narrative and identification make available to them. My intention is to devastate them with Morrison and uplift them with Walker, for Celie transforms the sentence of ugliness not through Prince Charming nor cosmetic surgery nor weight loss nor any of the traditional prescriptions for female self-creation. Instead, Walker's Celie transfigures from ugliness not into beauty, but into personal empowerment catalyzed by female community, meaningful work, economic independence, sexual sovereignty, and loving recognition of others. Women in the class respond particularly favorably to *The Color Purple* because, I think, it enables them to imagine themselves escaping social judgments of their bodies.

When the class seems adept at articulating this transformation, I use it as an opportunity to move among racism, sexism, and disability by differentiating between what I call the traditional "narrative of overcoming" and another story I term the "narrative of resistance," both of which are common disability narratives. Although both narratives are affirmative and perhaps related, an essential distinction needs to be made. The conventional "narrative of overcoming" suggests that one's body is the recalcitrant object that must be surmounted, often either by some physical or psychological

feat of rehabilitation or by a spiritual transcendence of the anomalous body. In contrast, the "narrative of resistance" claims rather than transcends the body, rejecting the traditional pronouncement of its inferiority and asserting the right of that body to be as it is. The notion of "resistance" thus locates the disabled or otherwise disapproved body within a cultural environment in which norms create deviance while the concept of "overcoming" places the deviance within the body deemed aberrant.

If on the one hand the novels act as touchstones for an identifying understanding, on the other hand they also arouse the most profound resistance among students. In both Morrison's and Walker's novels a simplistic reading suggests that the women are victims and the men are perpetrators. Although I offer ample textual evidence that no easy polarity between innocent women and guilty men is supported by the texts, the subjects of incest and rape that the novels explore always spark discussions in which some students usually take entrenched positions which pit men against women. The conflict that is sometimes fueled is exacerbated by the issue of racial solidarity and is shot through with suggestions of betrayal on both sides. Sometimes in class discussions, a great deal of hostility between men and women emerges that I must try to process sensitively and equitably. There are also always resistances to the critique of beauty that follow the logic that to reject beauty standards is to reject men. In every class, I feel that some students leave with the conviction that the course is essentially anti-male, no matter how much I attempt to present complexity and draw parallels among racism, sexism and ableism. The journals indicate that a few students choose to see beauty as innocent and me as a curmudgeon. Most often, some of the men hold this view, perhaps because they are emotionally identified with the male characters in the novels rather than with the women or perhaps because beauty is less anxiety provoking for them.

In conclusion, I need perhaps to offer a caveat concerning the position I have advocated so unequivocally here. It is important to recognize the limitations of the methodology that underlies the course that I am describing. By relating a variety of forms of social stigmatization, one risks failing to make clear the specificity, the distinct character, of each form. In comparing the disability category with race or gender systems, one must be vigilant not to conflate them so as to suggest that racial categorization, for example, is the same thing as disability, but simply in another form. The distinguishing aspects of disability such as physical pain, impairment, onset and origin, social milieu, specific economic concerns, and the like must not be erased by the move toward embracing a minority model. Nor should we fall into the simplistic equation I often hear either that "everybody has a disability of some sort" or that "being a woman (or black) is a disability." Comparing various forms of marginalized identities also risks invoking unproductive attempts to determine a hierarchy of oppression. I try with varying degrees of success to shift discussions of who suffers more than whom into examinations of complexity, interrelatedness, and uniqueness. While it is useful and illuminating to make comparisons and seek out underlying similarities among stigmatizing processes, it is equally important to particularize each identity so as to address precisely how it works in the world and how its attribution affects the persons involved.

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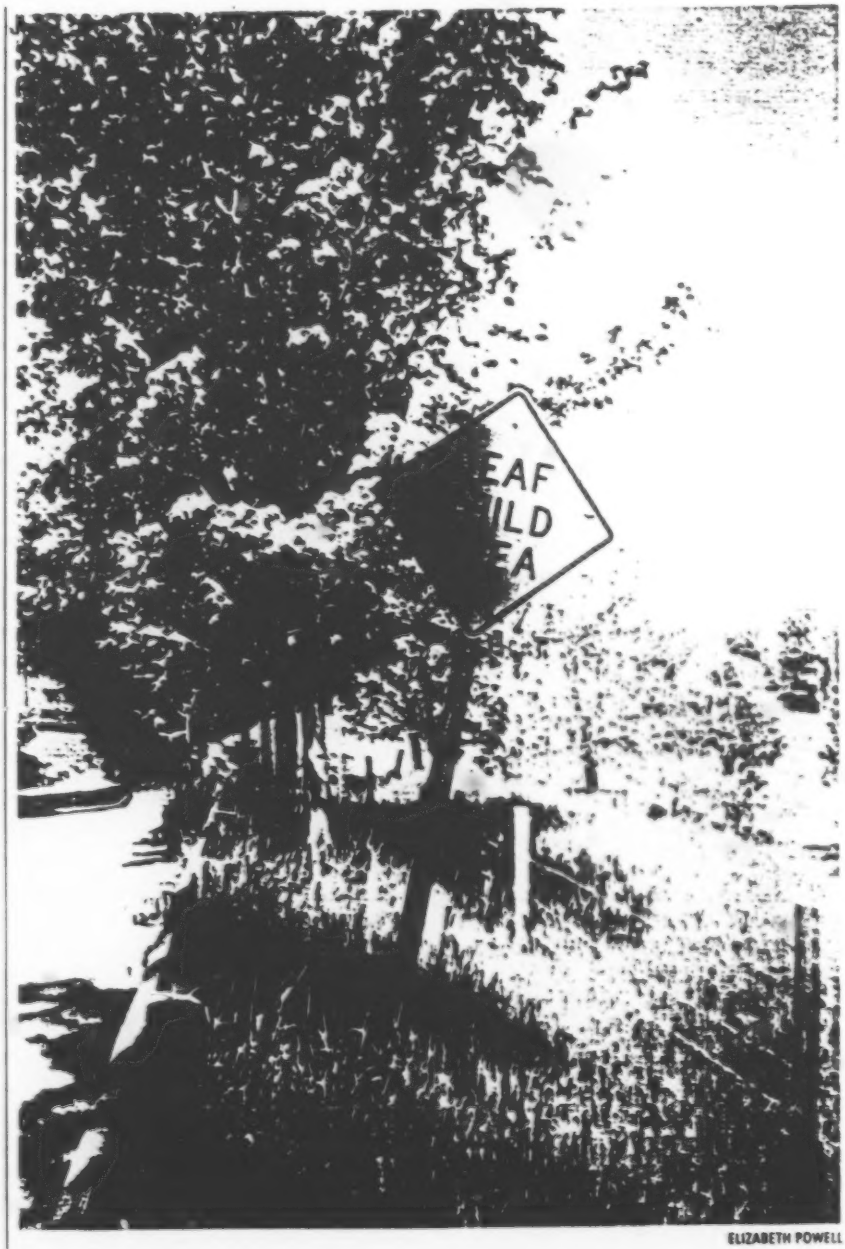
'Silence Is Not Without Voice':
Including Deaf Culture Within Multicultural Curricula

BY H. DIRKSEN L. BAUMAN AND JENNIFER DRAKE

At a time when universities work to incorporate multicultural curricula and canon revisions, they still perpetuate the pathologization of Deaf culture, language, and literature.[1] Most universities have yet to realize that Deaf people are not a loosely knit group of audiologically impaired individuals, but are, rather, a linguistic and cultural minority whose complex history, language, and literature warrant sustained recognition. Only a handful of American universities, for example, presently accept American Sign Language for legitimate language credit. As social science and humanities departments do not perceive Deaf studies to fall within their curricular domain, the study of "deafness" becomes relegated to special education departments—discursive straightjackets that confine Deaf culture to pathological constructions.

But what can a predominantly "hearing" university without a Deaf studies department do to rewrite these misunderstandings about the Deaf community? This is a question that we have been asking for different reasons and from different positions. When Dirksen crossed the border into a Deaf cultural space as a dormitory supervisor at the Colorado School for the Deaf and the Blind, he began to redefine his own pathological notions about Deaf persons. The Deaf students and faculty were not isolated and linguistically deprived as he had assumed; rather, they enjoyed a strong sense of community based on an "official" language. He, not the Deaf, became the linguistic outsider. Upon returning to a university setting, Dirksen found that even "progressive" language and literature faculty did not recognize American Sign Language as an "official" language or Deaf identity as a cultural identity.



ELIZABETH POWELL

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Over the past few summers Jennifer had been creating the curriculum for "Narratives of Struggle," a writing course exploring the centrality of so-called marginal communities in forging American (multi)culture. When Dirksen became co-instructor for the course, the personal and pedagogical benefits of linking Jennifer's work in multicultural studies with Dirksen's work on Deaf culture became obvious. We hoped that the multicultural context of the course would encourage an engaged reading of Deafness as culture rather than deafness as disability, and that the texts on Deaf studies would disrupt hearing teachers' and students' reductive ways of thinking about culture, identity, and community.

> Discussing Deaf language and culture in a multicultural context encouraged students to consider that American Sign Language is a "real" language and that the Deaf are a "real" cultural community.

We taught "Narratives of Struggle" as part of the 1994 Binghamton Enrichment Program (BEP) at SUNY's Binghamton University. BEP is part of New York State's Educational Opportunity Program (EOP) at Binghamton, which provides academic support to students from educationally and economically disadvantaged backgrounds. As such, students in the Binghamton Enrichment Program come from the working class or working poor; some come from group homes or foster care; many grew up in single-parent families; most are from New York City, though a few live upstate; and the majority are of African, Caribbean, Latino, and/or Asian descent.

Students enrolled in "Narratives of Struggle" also enrolled in "Media (Ill)Literacy and Self-Governance," taught by Kassie Fleisher. While the media studies course taught students to read the media's representations of "truth" in critical and complex ways, our writing course looked at texts that bell hooks would call "critical fictions"—texts that resist dominant discourses, challenge our expectations of what "literature" is/does, and require the development of engaged reading strategies. Hooks's essay "Narratives of Struggle," in Philomena Mariani's *Critical Fictions: The Politics of Imaginative Writing*, served as the template for the course, providing students with a critical vocabulary—"(de)colonization," "political self-recovery," "resistance," "imagination"—that they could use, and struggle with, throughout the course.

Each week had its own thematic focus, such as "Resisting Silences/Finding Voices," "Hybridity and Cultural Survival," and "(De)Colonization, Coalition Building, and Difference." At the start of each week the class wrestled with the meanings and implications of these titles by brainstorming associations on the chalkboard, unpacking dictionary definitions, returning to hooks's essay, and playing with the critical possibilities suggested by these title phrases.

Discussions of Deaf culture first occurred directly after reading Maxine Hong Kingston's "Song for a Barbarian Reed Pipe" during the "Resisting Silences/Finding Voices" week. This juxtaposition of texts and cultures worked to extend and to complicate the discussions of language and (multi)cultural identity, voice, and silence that we had begun in response to Kingston's work. Student facilitator Vivian Lei began a lively discussion about whether or not silences can work as a strategy of resistance and about how one person's silence is another person's expressiveness—think of Kingston's black paintings "full of possibility," about to reveal "mighty operas." Faced with the difference between Kingston's empowering reading of her own paintings and her teacher's pathologization of them, students began to talk about negotiating two or more languages and cultures. While some students focused on their own and Kingston's struggles to live "inbetween" and the pressure to assimilate, others described the benefits of drawing on two languages and cultural traditions, pointing out that "inbetweenness" might be lived not as culture clash but as a powerful position from which to speak and construct personal and community identities.

These conversations about language, culture, assimilation, and resistance provided a strong transition into discussions of Deaf culture as represented in Mark Medoff's play *Children of a Lesser God* and excerpts from Bernard Bragg's *Lessons in Laughter: The Autobiography of a Deaf Actor*, as signed to Eugene Bergman. Bragg's autobiography raises issues of the role of education as a means to coerce assimilation into "hearing" culture. Student facilitators Silvia Sanchez and Sabrina Lebron led the class through a close reading of Bragg's title scene in which a hearing teacher forces his Deaf students to laugh like "humans," that is, hearing people. Students were appalled that hearing culture could be so coercive and violent in the name of education.

We then moved on to Medoff's play, which also takes up the role of education in disciplining "cultural subjects." In addition, since Medoff is a hearing playwright, the play opens up discussion about "hearing" representations of Deaf persons. These issues of representation become especially pronounced when the written text of the play is juxtaposed with the film version. Silvia and Sabrina, for example, brought in film clips in order to illustrate the film's depoliticization of Deafness in favor of the love story, which, they agreed, was more likely to sell movie tickets. Reading and watching these two textual representations of Deafness as imagined by hearing people encouraged the class to reflect upon our own situation as a hearing classroom talking about Deaf culture. In this situation, hearing students and teachers might think of themselves not as speaking in place of Deaf people—for Deaf people may "speak" through texts and invited lecturers and performers—but rather, as hearing people engaging in self-reflective conversation about the audist oppression of the Deaf community.

> Students began to see that the family is not the only site for the transmission of cultural identity and that communities include, and are built from, our differences and multiple allegiances.

Student Youlla Pierre chose to write one of her papers about *Children of a Lesser God* in order to explore more fully dominant cultural assumptions about the

Deaf community. In the following passage, she articulates the differences between "hearing" and "listening," "silence" and "deafness:"

> Hearing is when you have heard what a person has said and you learn and empathize with that person. . . . Deaf means that due to biological reasons you were born without the ability to hear voices. It could also mean that you are unwilling to hear. The word silence means not speaking with your voice or it could also mean that you, unwillingly or willingly, want to communicate using other methods . . . [The deaf] have the knowledge to communicate in other ways . . . that may not be known to us . . . Maybe that makes us hearing people the silent ones to them.

Youlla went on to illustrate her ideas by writing about two major characters in the play: Sarah is a strong Deaf woman and James, Sarah's hearing husband and a teacher at the school for the Deaf, tries to teach Sarah to speak. Drawing on Friere's discussion of the "deposits" made in banking education and hooks's discussion of colonized minds, Youlla writes:

> James had a colonized mind . . . James became fearful of Sarah's independence because what would society think of a person who cannot overpower or as they would put it nicely, "help" a "disabled" person? . . . And since society had thrust upon him the idea that he had to take care of her . . . he thought that society would think less of him because he would not be able to control his "disabled" child. So because of that feeling, James ended up turning a "deaf" ear to Sarah . . . He only thought of himself and his need for her to [talk]. He did not leave himself any room to empathize with Sarah at all.

In her paper, Youlla continued to connect the inability to "hear" with the inability to listen and to empathize in order to argue that the dominant culture is "disabled" by its inability to listen to the "voices" of different communities. By creating the distinction between biological and empathetic deafness, Youlla articulated a convincing argument for depathologizing Deaf identity.

Clearly, discussing Deaf language and culture in a multicultural context encouraged students to consider that American Sign Language is a "real" language and that the Deaf are a "real" cultural community. For example, a paper by Amoy Chambers argued that bell hooks's call for "political self-recovery" requires the use of so-called "minority" languages like American Sign Language. Reading a scene from the film in which Sarah starts dancing with James but ends up dancing with herself and loving it, Amoy suggests that Sarah resists the label "disabled" by claiming an identity based on the powerful expressiveness of her body's movements in dance and sign. Amoy also links the political and cultural struggles of the Deaf community to other resistance movements:

> If sign language is a recognized language, then why is it not implemented in our curriculum as other languages are? So, society is overtly disregarding another culture, as it always does . . . society is not willing to acknowledge subjects/people that are different.

As the course continued, this acknowledgement of Deaf persons as cultural subjects dovetailed with discussions about identity-formation within multiple communities, including educational institutions such as the classroom and the university where our discussions were taking place. Students began to see that the family is not the only site for the transmission of cultural identity and that communities include, and are built from, our differences and multiple allegiances.

Including texts about Deaf culture in a multicultural curriculum demonstrated to students that "culture" cannot be thought of monolithically only in terms of "race." This realization opened the way for strong discussions of essays by Gloria Anzaldúa and Audre Lorde, in which the writers resist bearing allegiance to one community/self at the expense of another. In fact, students began to think about Anzaldúa's and Lorde's lesbianism in terms of "culture" and "community" and so, congruent with our discussions of Deaf culture, began to move away from a reductive pathologization of homosexuality. In later weeks, students continued to talk about the Deaf, gays, lesbians, and virtually all American cultures and subjectivities as hybrid, multicultural identities and so began to link various resistance struggles to their own struggles against racism and classism.

When approached with critical awareness, incorporating Deaf culture into multicultural curricula can bear substantial rewards for both Deaf and hearing communities. For the Deaf, recontextualizing Deaf identity in a cultural framework alongside Latinos, African-Americans, Chinese-Americans, gays and lesbians, and other cultural/racial/ethnic groups represents significant advancement toward the recognition that the Deaf community is a linguistic minority in the United States. In addition, hearing students introduced to the relevant historical, political, and social issues surrounding Deaf culture are encouraged to expand and to challenge their existing notions of multiculturalism, disability, and language. Such expansion of terms becomes a useful means of developing a wider, more inclusive critical consciousness among students and teachers whose notions of multiculturalism tend to overdetermine race at the expense of other significant and simultaneous sites of difference. Such reciprocal benefits to the Deaf and hearing communities serve to emancipate both from oppressive misconceptions about disability, language, and cultural identity.

Most universities have yet to realize that Deaf people are not a loosely knit group of audiologically impaired individuals, but are, rather, a linguistic and cultural minority whose complex history, language, and literature warrant sustained recognition.

NOTE

[1]We use "Deaf," rather than "deaf," in order to distinguish between Deaf people who identify with Deaf culture and deaf people who do not. This distinction also helps to clarify the differences between Deaf education (bilingual/bicultural education) and deaf education (the historically hearing-dominated forms of education based on the medical view of deafness). □

A Review of Deaf Studies Curricula

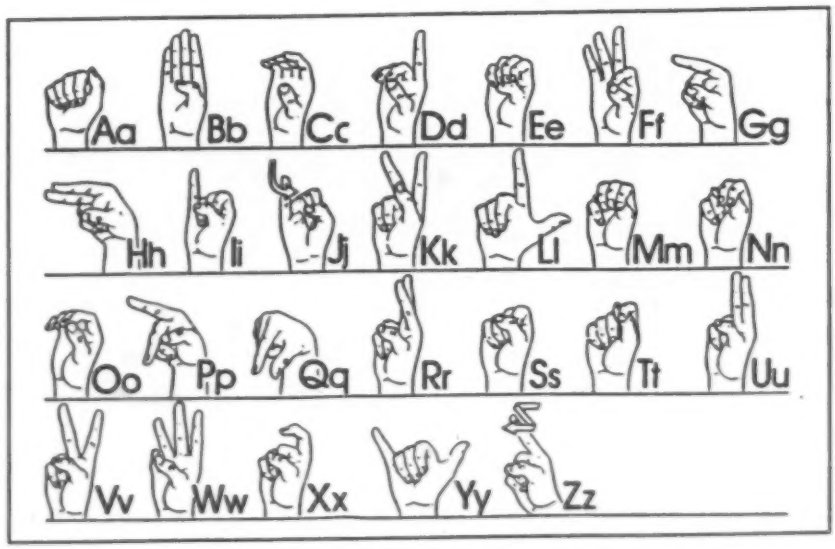
BY H. DIRKSEN L. BAUMAN

Teachers who wish to create multicultural reading lists for their courses may readily choose texts from Native-American, African-American, or Asian-American writers. However, texts from Deaf Americans may not as immediately come to mind. The purpose of this review, then, is to provide teachers with an overview of curricular material which demonstrates the centrality rather than marginality of the cultural, political, and linguistic issues raised by Deaf studies.

Next to guest lecturers, one of the most effective means for letting Deaf persons "speak" in a hearing classroom, is through the use of video-texts. Dawn Sign Press, for example, has begun to produce the *ASL Literature Series*. The first video features signed narratives by Deaf storytellers Ben Bahan and Sam Supalla. While the *ASL Literature Series* is not voice interpreted, a workbook accompanies the videotapes so as to make the narratives accessible to hearing audiences. Also, the San Francisco Public Library has produced a series of videotapes, *American Culture: The Deaf Perspective*, which offer voice-interpreted interviews, discussions, and performances of plays and poems by Deaf performers. The signed texts in both tapes explore the dynamics of living in a hearing world that refuses to listen.

Introducing students to the emerging body of American Sign Language literature can awaken important questions that would have lain dormant otherwise: How does ASL literature challenge existing literary conventions and genres? How are these conventions linked to larger sociopolitical issues of power, knowledge, and linguistic domination? How does the visual body-text of ASL change the way that we talk about a literary "text"? These and other questions may encourage students to make connections between literary and hegemonic practices.

While exploring the creative field of video-texts, Deaf authors have also produced literature in written English that challenges normative ideas of culture, disability, and literature. The recent *Eyes of Desire: A Deaf Gay and Lesbian Reader*, edited by Raymond Luczak, is a complex, multicultural, heteroglossic reader full of "critical fictions" which take the forms of fiction, poetry, creative essays, TTY phone conversations, letters in "Deaf English," interviews, photographs, and personal narratives translated from ASL. These texts frequently engage the emotional, social, and political issues involved in claiming hybrid identities and developing multiple allegiances through community and coalition building. This anthology encourages readers to raise a number of important questions: What paradigm may be used for underrepresented groups—like the Deaf—to unite while still respecting various sites of difference? What sort of model may be used to express this flexible, non-monolithic version of (Deaf) culture? How is resisting audism complicit (or not) with resisting homophobia—even within the Deaf community?



While not as diverse as *Eyes of Desire*, *No Walls of Stone: An Anthology of Literature by Deaf and Hard of Hearing Writers*, edited by Jill Jepson, offers some of the most accomplished writing from the Deaf community to date. While many authors in *No Walls* are not Deaf but deaf[1], some Deaf authors have been included whose writing operates as a form of "resistance literature." Willy Conley's one-act play, "The Hearing Test," for example, dramatizes the medical establishment's relentless pursuit to "cure" deafness. "The Hearing Test" introduces the controversial topic of the cochlear implant, a pressing issue for the Deaf community which provokes questions that most hearing students would not otherwise entertain: Why wouldn't most Deaf persons want to undergo surgery if they could improve their hearing? Is the implant a medical advancement or the latest manifestation of the eugenics movement? What sort of information and images do hearing parents receive about Deaf culture? Why do parents fear "losing" a child to Deaf culture? Why do so few hearing parents learn ASL? Conley's play and other poems and narratives in *No Walls of Stone* all offer ways that Deaf "voices" may be heard in hearing classrooms.

The contemporary issues in *Eyes of Desire* and *No Walls of Stone* contrast in

interesting ways with *Angels and Outcasts: An Anthology of Deaf Characters in Literature*, edited by Trent Batson and Eugene Bergman. This collection offers a nineteenth- and twentieth-century collection of deaf characters by such well-known authors as Dickens, Turgenev, de Maupassant, Welty, and Malamud. As *Angels and Outcasts* concludes with a selection of Deaf writers, this text encourages readers to contrast hearing versions of deaf characters with autobiographical narratives of Deaf persons. In addition to *Angels and Outcasts*, Brian Grant's *The Quiet Ear: Deafness in Literature* offers an even more extensive range of the use of d/Deaf characters as symbols in literature. Although these selections tend to be too short to sustain in-depth critical inquiry, this text provides good material for curricular planning and further research.

> One of the most effective means for letting Deaf persons "speak" in a hearing classroom, is through the use of video-texts.

While these anthologies present diverse literary voices, Deaf studies is also producing scholarly texts that examine the complexities of Deaf history. *Deaf History Unveiled: Interpretations from the New Scholarship*, edited by John Vickery Van Cleve, initiates a new level of scholarship in the field of Deaf history, which, as the editor notes, "as recently as the 1970s . . . did not exist" (ix). This internaticnal collection of essays rewrites misunderstandings of Deaf history, revealing the broad mechanisms of audist oppression which have operated for centuries under the guise of benevolent paternalism. Susan Plann's essay, "Pedro Ponce de Leon: Myth and Reality," for example, offers a new perspective on the origins of deaf education by recognizing the invaluable contributions of Deaf pupils to the history of deaf education. Tricia Leakey's essay discusses how vocational education has been used in Deaf and African-American communities as a means to limit the upward mobility of both minority groups. These and other essays would be especially productive in a class that encourages students to examine the distribution of power within educational institutions. Reading such a new book in a new field is a reminder that reclaiming history is at the heart of resistance and political self-recovery.

Another text which works to reclaim Deaf history and to define Deaf Culture is Padden and Humphries's *Deaf in America: Voices from a Culture*, which offers a solid overview of Deaf culture and history, revealing social mores and patterns of cultural transmission. In addition, Harlan Lane's polemical *The Mask of Benevolence* is the first to benefit from Foucauldian historical analysis as it aligns the audist medical and education establishments with the rise of other normalizing disciplinary institutions. Lane's book is also one of the first to discuss the oppression of the Deaf community as an issue of colonization. *The Mask of Benevolence* leads students towards dialogue which could help define and widen perspectives on colonization and on Deaf history. Engaging these issues of Deaf history raises valuable historiographical questions: What are the similarities between colonial and deaf education? How is the history of the Deaf community par-

> Introducing students to the emerging body of American Sign Language literature can awaken important questions that would have lain dormant otherwise.

allel (and not) to that of other ethnic minorities and immigrant communities? What are potential strategies to enfranchise deaf education?

While this last question is being discussed among Deaf activists, it may also be asked of hearing students and teachers so as to compel us all to confront the political implications of pedagogical and curricular issues. As editor of *American Deaf Culture: An Anthology*, Sherman Wilcox assembles useful readings on bilingual and bicultural education as a means of breaking what Friere calls the "culture of silence" that surrounds disenfranchised groups. Indeed, Wilcox notes that the "culture of silence must be broken from within and the first blow must come from the Deaf student" (188). While this is undoubtedly the case, hearing students and teachers may also engage in a critical examination of their own pathologized notions about Deaf culture—so as to liberate their own minds from the chains that bind both the oppressed and the oppressor.

Including discussions of Deaf culture in the university setting will hopefully be a productive means to rewrite the widespread misunderstandings of the Deaf community. The more that discussions on the Deaf are framed in a cultural rather than pathological perspective within the university, the more likely it is that hearing persons will begin to accept ASL as a legitimate language and the users of that language as a legitimate linguistic minority. At the same time, hearing students and teachers may be encouraged to challenge their own definitions of language, culture, and literature. In the end, we find that the issues raised by Deaf studies are at the heart of developing a truly (multi)cultural perspective.

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NOTE

[1]See the Note at the end of the article by Bauman and Drake in this issue. □

A Review of Harlan Lane's *The Mask of Benevolence:* Disabling the Deaf Community[1]

BY LENNARD J. DAVIS

The fact that I cannot write this review in American Sign Language (ASL) tellingly reveals the complex imbalances in power facing deaf Americans. Although the majority of deaf people speak ASL, their language is not widely known nor is it even accepted as a legitimate language by the hearing world. On the other hand, any deaf person in this nation is expected to read and speak English. Harlan Lane, in this impassioned and damning indictment of the hearing establishment, demonstrates the legitimacy of sign as a language and urges us to see the deaf not as a stigmatized, medicalized, disabled category but as a linguistic sub-group within a dominant majority. Lane shows how this history of spurning the natural language of the deaf in favor of a variety of other schemes will always leave deaf people with an inferior education and a dubious social status.

A current MacArthur Fellow and University Distinguished Professor of psychology at Northeastern University, Harlan Lane, himself hearing, has written extensively on the history of the deaf, including such works as *When the Mind Hears* and *The Wild Boy of Aveyron.* In *The Mask of Benevolence,* he now moves from history to the current moment. This book is a strong polemic criticizing every aspect of the way the deaf community is treated and educated by the hearing or, as he calls them, the "audist" world. Lane's attack is political as well as academic. Using Michel Foucault's work, he describes the way deafness has been constructed as a deviance, one that has become an object of surveillance and punishment achieved through rituals of control. Also using the work of Edward Said, Lane sees the deaf community as colonized by the imperial forces of the hearing majority.

Beginning on an anthropological note, Lane examines lists of adjectives used in the literature of colonization to describe Africans and shows how these same words are now applied to deaf people by the hearing professionals who study them. As Lane says: "Like the paternalism of the colonizers, hearing paternalism begins with defective perception, because it superimposes its image of the familiar world of hearing people on the unfamiliar world of deaf people" (37). The aim of these professionals is to "civilize" the deaf, as the colonists intended to do with the natives, without realizing that the deaf have their own values and structures within their community.

For Lane, much of this civilizing effect is centered around the teaching of language. Although the bulk of work by deaf and hearing linguists indicates that the earlier a child acquires language the better, and that deaf children can learn signing much earlier than they can learn to speak orally, the overwhelming effort in deaf education has been to avoid ASL. The educators favor teaching English, either signed versions of English syntax or spoken English, because they feel the child must grow up in a world that only speaks the national language. But Lane shows that this system of teaching is a complete failure, with only four percent of deaf graduates able to read complex subject matter. Despite the banning of ASL in much of deaf education, the fact is that the students who do best are the ten percent of deaf children born to deaf parents, that is, those who learned ASL from infancy.

Lane would like the hearing establishment to think of the deaf as a bilingual community. Experts in education now widely accept the idea that linguistic sub-groups like Hispanics will do better if their native language is taught in school along with English. Lane argues, logically, that the deaf are no exception to this generally held wisdom and sees reluctance to teach the deaf bilingually as a sign of ethnocentrism. "Residential schools for deaf children meted out severe punishment for using ASL, and in federal boarding schools for Indians, children were beaten for using American Indian languages" (116).

Lane helps us to realize the especially complex social and cultural positioning of the deaf. Although a deaf child and a Hispanic child can be compared, there are crucial differences, since ninety percent of deaf children are born to hearing parents. Lane says that being deaf is like being gay, in this sense, since "most members of the minority do not share their minority identity with their parents and cannot develop it at home" (21). And he points out that being deaf is not really comparable to being disabled, since the deaf, unlike the disabled, willingly segregate themselves into residential schools and later deaf communities and marriages to share their own language and culture.

In addition to being colonized, deafness is medicalized in a Foucauldean "ritual of power." There is a chilling similarity between Foucault's vision of the panoptic penitentiary and a deaf child's session at the audiologist:

> The child is seated, wearing earphones, in a small steel room. The audiologist inspects and directs him through a large glass window ... [and] gives instructions to the child in the soundproof room.... What is important is the quantification, the process, the sentencing—it has little predictive or practical value; neither "totally" nor "profoundly" nor "severely" deaf children can understand normal speech, even with powerful hearing aids.

Lane sees this ritual as another form of courtroom sentencing that "exists largely to perpetuate a certain social order" (25). Even more disturbing in the process of medicalizing deafness is the rush to implant in deaf children electronic cochlear devices—bionic ears, in effect. These devices have not, according to Lane, been sufficiently tested by the FDA, nor do they produce much more than vague sounds in the ears of deaf children. Nonetheless, these devices are imposed on the deaf by distraught hearing parents and desperate deaf educators, together with patent-owning companies. Lane describes, in a scene that makes medieval torture seem tame, how the surgeon saws and drills through the skull and finally snakes a wire into the ear. "The exquisitely detailed microstructure of the inner ear is often ripped apart as the electrode weaves its way, crushing cells and perforating membranes; if there was any residual hearing in the ear, it is almost certainly destroyed" (4). According to Lane, a child's ability to hear and speak are minimally improved, if at all, by such a difficult procedure. Indeed, many teenagers who had cochlear implants when they were younger refuse to use the devices when they reach an age of independence.

Lane wants to see deaf people take control of their lives instead of being subjected to the audist establishment. He advocates going back to the practice of the nineteenth century when the majority of teachers of the deaf were deaf themselves, as Helen Keller's teacher was herself blind. Deaf psychologists and linguists should be the ones to devise tests for deaf children, if such tests are even necessary, and the hearing world should relinquish its paternalistic control over the deaf. When the deaf leader Jean-Francois Mercurio opened the International Conference on Sign Language in July 1990, he did so by smashing a hearing aid with a sledgehammer, recognizing that the technology of "audism" had become the symbolic chains of the deaf.

Certainly, one can legitimately argue with Lane that as much as the deaf have their own community, they do have to function in a hearing world. In *Children of a Lesser God*, Marlee Maitland played a young woman who refuses to learn to speak, but who is then paradoxically dependent on her hearing companion. Lane really does not address this issue and the book could be even more convincing if he explained how in a deaf-centered educational system speech would be dealt with.

Having grown up in a deaf family, I found Lane's book to be an exciting breakthrough. As a child, I had never thought of deafness as anything more than a problematic handicap. By theorizing deafness, and politicizing the issues, Lane has articulated a means to empowerment. I read this book with the same thrill of recognition I felt when first reading other theorists of oppression in the realm of class, nationality, race, and gender. Now progressives will have to add deafness to that list, as they understand that in addition to the many screaming injustices the dominant culture has perpetrated, there is another silent yet articulate one in its very midst.

NOTE

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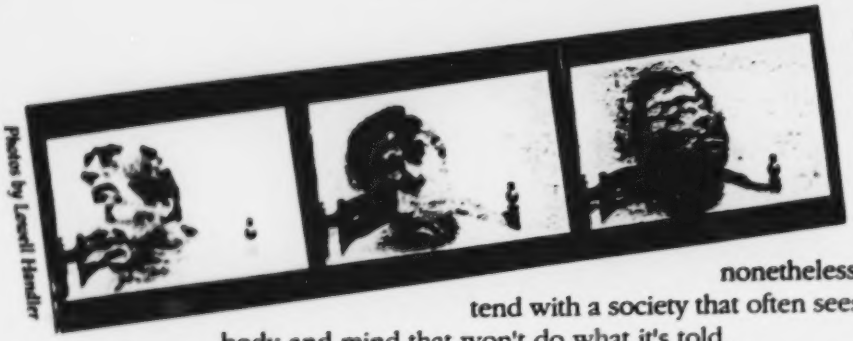

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I Am Not One of the

By Cheryl Marie Wade

I am not one of the physically challenged —

I'm a sock in the eye with gnarled fist
I'm a French kiss with cleft tongue
I'm orthopedic shoes sewn on a last of your fears

I am not one of the differently abled —

I'm an epitaph for a million imperfect babies left untreated
I'm an ikon carved from bones in a mass grave at Tiergarten,
Germany
I'm withered legs hidden with a blanket

I am not one of the able disabled —

I'm a black panther with green eyes and scars like a picket fence
I'm pink lace panties teasing a stub of milk white thigh
I'm the Evil Eye

I'm the first cell divided
I'm mud that talks
I'm Eve I'm Kali
I'm The Mountain That Never Moves
I've been forever I'll be here forever
I'm the Gimp
I'm the Cripple
I'm the Crazy Lady

I'm The Woman With Juice

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Copyright © 1987 by Cheryl Marie Wade. This poem is dedicated "to all my disabled sisters, to the activists in the streets and on the stages, to the millions of Sharon Kowalskis without a Karen Thompson, to all my sisters and brothers in the pits, closets, and institutions of enlightened societies everywhere." It originally appeared in *Sinister Wisdom*.

100

CRIPPLE LULLABYE

BY CHERYL MARIE WADE

I'm trickster coyote in a gnarly-bone suit
I'm a fate worse than death in shit-kickin' boots

I'm the nightmare booga you flirt with in dreams
'Cause I emphatically demonstrate: It ain't what it seems

I'm a whisper, I'm a heartbeat, I'm "that accident", and goodbye
One thing I am not is a reason to die.

I'm homeless in the driveway of your manicured street
I'm Evening Magazine's SuperCrip of the Week

I'm the girl in the doorway with no illusions to spare
I'm a kid dosed on chemo, so who said life is fair

I'm a whisper, I'm a heartbeat, I'm "let's call it suicide", and a sigh
One thing I am not is a reason to die.

I'm the poster child with doom-dipped eyes
I'm the ancient remnant set adrift on ice

I'm that Valley girl, you know, dying of thin
I'm all that is left of the Cheshire Cat's grin

I'm the Wheelchair Athlete, I'm every dead Baby Doe
I'm Earth's last volcano, and I am ready to blow

I'm a whisper, I'm a heartbeat, I'm a genocide survivor, and Why?
One thing I am not is a reason to die.

I am not a reason to die.

Reprinted from *MOUTH!* magazine.

Disability Studies Bibliography

BY THE DISABILITY STUDIES PROJECT OF HUNTER COLLEGE

In general, books and articles were selected because they are based on a social/cultural/political model of disability. Other references were included which can be used as tools to further the understanding of how disability has been represented in various cultural products. These references were drawn from numerous sources and databases (e.g., social science, humanities, and education indexes).

This April 1995 bibliography will continue to evolve and we welcome your input in developing it further. It is by no means an exhaustive list. Please send references to: The Disability Studies Project, Hunter College, 1016 West, 695 Park Avenue, New York NY 10021; phone 212-772-4723; fax 212-772-4941.

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Selected journals with issues devoted to various topics in Disability Studies

Journal of Social Issues, *4*(4) 1948
Journal of Social Issues, *44*(1) 1988
The Minnesota Review, *ns40*, Spring/Summer 1993—The Politics of AIDS
Policy Studies Journal, *21*(4), 1993–Disability Issues in Public Policy

And journals/magazines worth examining anytime

The Disability Rag and Resource
Disability and Society
Disability Studies Quarterly □

Radical Teacher seeks articles and prospectuses on:

Privatizing Education

Has the movement for universal public education that began 150 years ago been permanently reversed? How should radicals in education relate to privatization efforts that abound now?

They are diverse. Some corporations are running public schools for profit or building for-profit schools in competition with public education. Others have long influenced it by providing "free" materials for use in public schools. Channel One now reaches millions of kids in their classrooms. Corporations are spending more to educate their workers directly. Many states now have charter schools, run independently by parents and teachers but with funding from public education budgets. There are alternative schools within city school systems, some with foundation support. There are street academies, fundamentalist schools, private schools to maintain segregation. Cutbacks in support for public universities drive them to seek more corporate funds.

Obviously, some of these movements express a right-wing assault on government, public education, teachers, integration, democracy. But some also involve participation of teachers, parents, and students in shaping education. How do we distinguish left from right critiques of public schooling? Has the rhetoric of multiculturalism contributed to the evaporation of a liberal project of common schooling? Do *we* need to support the liberal project? How do we make a radical critique of it without inadvertently doing the work of the right? Can we challenge privatization and still claim that American society is marked by fundamental divisions? How can we?

For an issue of *Radical Teacher* we seek articles that respond to such questions, as well as case histories. For instance,

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- of charter schools, New Vision schools, home schooling, etc.: what good and bad things are happening in these ventures?
- of corporate interventions in public schools, and of progressive resistance and organizing;
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- of what is happening in and to universities as their work becomes more entangled with corporate interests and projects;
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